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ABSTRACT

The monograph presents, from the disabled consumer's perspective, a description and critique of independent living and attendant care services in Sweden. First, a brief description of Swedish welfare policy as it applies to the population as a whole is presented. Next, services available to people with disabilities are described with emphasis on personal assistance programs which help to keep disabled and elderly citizens out of institutions. These services are then evaluated based on available statistical material, contacts with providers and consumers of the services, and the disabled author's own experiences. These services include personal assistants, the county home health service, escort services, evening patrols, emergency call systems, and cluster housing. Assessment is in terms of administrative compartmentalization, economic and other obstacles to deinstitutionalization, professionalism and limited consumer input, decentralized financial responsibility and regional inequality, and limited consumer choices. Noted is the formation of the Stockholm Independent Living Group of disabled consumers concerned with increasing choices in personal assistance alternatives. Research issues in the areas of needs assessment, redefining institutions, degree of consumer control, quality criteria, and program design are identified. An appendix contains design criteria for personal assistance programs. Finally, four commentaries by American rehabilitation experts are added. (DB)

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INDEPENDENT LIVING AND ATTENDANT CARE IN SWEDEN: A CONSUMER PERSPECTIVE

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Spring 1986

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The shortcomings of this monograph are entirely my responsibility and can in no way be attributed to any of the above listed persons or organizations.

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February 1986

ABOUT THE AUTHOR

Dr. Ratzka has been using personal assistants since 1961, when he became disabled by polio in his native West Germany. He received his academic training at the University of California at Los Angeles (B.A. in Sociology, M.S. in Business Administration, Ph.D. in Management) and the University of Stockholm (fil. kand. in Psychology). Since 1973 he has had his base in Stockholm, Sweden where he works as research economist at the School of Architecture, Institute of Technology. His current research interests include cost-revenue studies on accessibility in housing, de-institutionalization, and personal assistance for people with disabilities and older persons.

Dr. Ratzka has been a consumer of personal assistance services in West Germany, the United States, and Sweden. Influenced by his frequent contacts with the Independent Living Movement in the US and other countries he took the initiative for setting up a pilot project in Stockholm where consumers of personal assistance organize and administer their own individual service.

NOTE TO THE READER

The title of this monograph contains the expression "a consumer perspective". Implied here is the notion that there is no "value free" treatment of social policy and that there are several viewpoints from which to approach attendant care programs and social services in general. Much of the existing work in this area, be it descriptive or analytic, is commissioned or undertaken by government bodies or service providers. As a natural consequence, such studies tend to focus on aspects such as budgetary requirements or the administrative needs of the agency and its workers. Seldom is the emphasis on the needs of the consumers of these services. While, for example, the discussion of costs invariably is paid a great deal of attention, the quality of the services—the variable that is uppermost in the consumer's mind—is quite often blatantly overlooked. Therefore, analysts and researchers who want to support the demands raised by people with disabilities for services which allow full participation and equality, have to propagate the notion of consumer-oriented research. Consumer-oriented research here means work which uses consumer-oriented criteria and, ideally, is consumer-initiated and controlled. The present study carried out under the auspices of the World Institute on Disability, a consumer-run policy research and training institute, is an attempt in this direction.

I find it difficult to give a balanced analysis of Swedish social policy to a non-Swedish audience. There is a strong temptation to concentrate on the accomplishments of the Swedish system and to focus on the impressive array of cash payments and in-kind benefits that make one's material life as a person with an extensive disability so much easier in Sweden than in the other countries I have visited and lived in. Speaking abroad to disability advocates and service providers I feel very strongly that I am expected to provide positive examples of what can be accomplished by a country's population and politicians who, for the most, believe in equality—not only at the starting line but also at the finishing line—and who see economics not as an exercise in cutting taxes but as a means to improve the quality of life for as many as possible. And I do want to provide such examples.

On the other hand, Sweden is of course no paradise either, neither for disabled nor for non-disabled people. People with disabilities are still second class citizens in material terms as recent government investigations demonstrate. There is yet another problem area that deserves attention. The increasing professionalization of social services that I observe in several countries has come furthest in Sweden. As one of the negative effects of this development I see a growing dependence among persons with disabilities in many aspects of their lives, dependence on a large cadre of social workers and similar professionals. It is their job to assist us, but many times the services they are providing are not designed in a way which increases our

opportunities for self-direction; instead they often deprive us of possibilitities to exercise our own initiative, to use and develop our judgement and self-confidence. As a result, many of us do not feel in control of our own lives. In many countries the lack of material services makes people with disabilities openly dependent on the charitable inclinations of their surroundings and forces them into a restricted and undignified existence. In Sweden the mechanisms of dependence are much more subtle; many of us experience dissatisfaction, frustration, and despair without knowing where to look for the causes.

My critical analysis should in no way be interpreted as an attack against the existence and extent of these services, the political commitment which brought about the programs, and the underlying intentions of policy makers and service providers. It would be an unfortunate misunderstanding, if somebody would want to use the material presented here as an argument against "the welfare state". For people with extensive disabilities attendant care services are the very key to a dignified and productive life in the community. In my belief it is the government's responsibility to provide these services as a fundamental civil right.

My aim here is to draw attention to the more intangible and qualitative aspects of attendant care which impact on consumers' lives as powerfully as the quantitative extent of service provision. Such issues are power and control, self-determination, self-esteem, and quality of life. Hopefully, the monograph can contribute to a better appreciation of the difference between quantity and quality in service delivery, between the amount of hours provided on the one hand and the way they are delivered on the other, between the level of material means provided by the public and the level of control exercised by the individual consumer over how these resources are to be used, between being treated as an object and acting as a subject.

The initiative of STIL (Stockholm's Independent Living group) described in the text is an example for this distinction: The participants in STIL's pilot project advocate and defend the notion that it is government's responsibility to provide the financial resources for attendant care programs. But what they insist on is that consumers must be able, if they so choose, to organize their own service systems in order to obtain control over this important aspect of their lives.

I am well aware that the demand for consumer control may appear as a luxury to people who live in countries with no assistance programs whatsoever, to people who have to depend entirely on family or volunteers for these services, or to people who have to pay assistants out of their own pockets like my friend in California who spends a third of her modest annual income on such services. Thus, to many readers the problems addressed here might seem far removed from their every-day reality and too advanced. Yet with the continued rise of the Independent Living Movement people with

disabilities the world over will demand personal assistance programs. It will be of paramount importance that we, the consumers, take the initiative in shaping these services such that we gain greater independence and more personal power through them.

The Author

I. INTRODUCTION

One of the main aims of the growing Independent Living Movement[1], the international civil rights movement of people with disabilities, has been to gain control over the services that are necessary for participating in society on equal terms. Of these services attendant care has been identified by the movement as perhaps the most critical prerequisite for a dignified and productive life for persons with severe disabilities.

Attendant care, briefly, consists of assistance through paid workers with dressing, bathing, personal hygiene, household chores and all the daily activities that a person cannot perform by himself or herself. Other terms in use for the same service are home care, in-home support or home help. Sometimes the distinction is made between household related tasks which might be called home chore, home helper, domestic or home maker service and more person and body related work which is commonly referred to as personal care. Most of these terms are unsatisfactory. For one, they create the impression that assistance is needed only in the consumer's home implying that people with disabilities spend their day inactively at home and not in the community pursuing work, travel, social, and cultural activities like everybody else. Assistance at home as well as outside the home is the very key to the ability of persons with extensive disabilities to participate in their community and any language that suggests the opposite has to be avoided. Also, commonly used terms such as "attendant" and "care" carry institutional connotations and do not project the image of active and self-directed consumers of such services. In the following the use of "personal assistance" is suggested which is hoped to convey a more positive and less restrictive image.

Personal assistance in any country is far from being available to all individuals with disabilities who need it. Where the service does exist it is often not provided in the extent and the form which would permit consumers to realize their potential in gaining independence. Thus, in order to be able to influence legislators and policy makers, concerned consumers and service providers are gathering information on those existing personal assistance programs that contain features which have been shown to support the aims of consumers. Among the countries that have adopted a national personal assistance policy the Scandinavian countries are known for their extensive programs in this area. It is for these reasons that Swedish personal assistance schemes for persons with disabilities and older people are presented here.

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[1] For an account of history and ideology of the Independent Living Movement see DeJong, G., *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research*, Center for International Rehabilitation, East Lansing Michigan, 1979.

Comparative analysis in the area of social policy encounters many obstacles. Apart from insufficient opportunities for the sharing and exchanging of experiences across national borders one source of bias and misinformation consists of the fact that visitors engaged in exchanges of this type are typically not consumers of the services which they are reviewing. They face the problem of assessing service delivery programs of which neither they nor their hosts have direct experience. In many instances such information impedes comparative analysis and, ultimately, evaluation of the transferability of programs from one country to another. In the following monograph, the description of Swedish personal assistance programs is therefore supplemented by some analyses and assessments which are based on the author's experience as a consumer of these services.

Since people with disabilities are an integral part of the general population, social policy in this area cannot be viewed as isolated measures aimed at this particular segment of society but has to seen in the pertinent institutional framework and in the context of a country's total approach to income redistribution, social welfare, and health planning. Such a holistic view facilitates understanding, evaluation, and assessment of the transferability of individual programs from one social climate to another.

The presentation will therefore begin with a brief description of Swedish welfare policy and some of its more important features as they apply to the population as a whole. Next, an account of the services available to people with disabilities will be given. The focus of the report is on Swedish personal assistance programs. Such programs are available to a variety of groups, not just to persons with disabilities. Personal assistance services for people with disabilities are available for a range of situations such as assistance at work and school. Services for older and disabled citizens in their own homes are perhaps the most important prerequisite for keeping people out of institutions, as a brief survey of recent Swedish studies on de-institutionalization shows. The main body of the paper consists of a description and evaluation of such services based on statistical material as far as it is available, information collected through the author's contact with providers and consumers of the services as well as the author's own experiences. The remainder of the study is taken up by a discussion of some of the research issues raised in the presentation.

As a final introductory note, no specific references are made to the mentally retarded the reason being that all the programs described here are also available to this group. (The administration of the services might differ, since there is special legislation in this area.) Group homes and similar institutional or semi-institutional solutions for the mentally retarded, however, are not covered here.

II. SWEDISH SOCIAL WELFARE POLICY

Sweden is an industrialized country of some 8 million inhabitants who enjoy a relatively evenly distributed high standard of living. The extensive social welfare system for which Sweden is known dates back to the economic depression in the 1930's when the labor-oriented Social Democratic Party began its almost uninterrupted rule. In the Scandinavian tradition government is viewed as a form of mutual insurance for all where, ideally, each citizen contributes according to his or her ability through paying taxes and is entitled to services according to his or her needs. In this tradition government has adopted a comprehensive view as to the circumstances in which intervention and support of groups and individuals is called for. As a result, the definition of what areas of human endeavor are to be considered under the influence of the collective is in Sweden wider than in most other countries. The comprehensive view on social welfare policy is backed up by an impressive array of policy instruments which can be described here only very briefly.

Division of Responsibility

The Swedish social welfare system is administered by the three levels of government: central state, county councils, and local governments. The national government is responsible for issuing laws and regulations and their enforcement. In addition, functions such as social insurance, housing subsidies, labor market measures including vocational rehabilitation and education are administered at this level.

The country is divided into 24 county councils which are responsible primarily for health care and related areas such as medical rehabilitation, provision of technical aids to persons with disabilities, and programs for the mentally retarded.

On the third level of government, Sweden is divided into 280 municipalities charged with the provision of housing, social services, public transportation, and schools. Each level of government has taxing authority. There is revenue sharing from central government to the county councils and the municipalities for specific programs. Local governments enjoy a relatively large degree of autonomy in both the extent and the type of services delivered depending on the local tax base and local political priorities. It is for these reasons that the provision of certain social services varies widely across the country with severe consequences for the geographical mobility of persons with disabilities as will be developed.

National Insurance Benefits Available to All

The backbone of Swedish social policy is the National Social Insurance which covers health insurance, pensions, occupational injury, and unemployment insurance. Swedish citizens and residents are covered regardless of income. Except for a flat fee for some of the services the cost of the National Insurance is borne by national income tax funds. Here a few examples are presented for the extent and type of coverage under the insurance.

Hospital care is covered by the insurance except for a nominal daily fee. Outpatient visits at primary health centers, hospitals or at private physicians who are affiliated with the National Health Insurance cost between 40 SEK and 60 SEK in 1985 (1 SEK = $0.11 in 1985) which covers all the costs of consultation, diagnosis, treatment including physical therapy. For prescriptions there is a flat fee of 50 SEK. Travel expenses incurred in connection with these visits are also covered. Persons with severe chronic conditions requiring constant medications and supplies are entitled to free medicine.

Sick leave allowances correspond to 90 per cent of the income which the beneficiary would have earned, if he or she had not been ill. This amount is taxable and is paid from the second day after notice has been given to the local insurance office. If an illness continues for more than 6 days, a doctor's statement is needed. There is no limit to the amount of time for which this compensation can be paid but, usually, after 90 days the insurance office will take up the case and recommend action as to how the patient can return back to work or should apply for retraining or disability pension, if the condition seems to be of long-term nature.[2]

Pension benefits consist of old age, disability, and widows' and children's pensions. A disability allowance, for example, is granted to persons with functional impairment in order to provide compensation for the additional cost of living due to their disability. In 1984 this tax-free allowance paid to persons with extensive physical disabilities was 1,100 SEK a month. (For comparison, the average gross income of an industrial worker was approximately 8,500 SEK a month in 1984.) We will return to the disability allowance in the discussion of alternative funding of personal assistance services.

In connection with the birth of a child, with or without a disability, the parents are paid an allowance to compensate for the temporary loss of income. The father is entitled to 10 days' paid leave. In addition, both parents together receive the equivalent of a total of 260 days' income which they can share in any way they choose, before or after birth. Parents are also entitled

[2] The Federation of Social Insurance Offices, *Social Security in Sweden*, Stockholm, 1980, p. 21.

to a paid leave of absence of up to 60 days per child and per annum, for the temporary care of a sick child. After the eigth consecutive day a doctor's statement is required.[3] Considering the liberal rules for sick leave and child care it is surprising to note that the average rate of absenteeism from work in Sweden was 21 days in 1984.[4]

One of the main purposes of these insurance benefits is to encourage women's participation in the labor force. In 1978, 71 per cent of the women and 88 per cent of the men in the age bracket 16-64 were gainfully employed in Sweden.[5] For people with disabilities the corresponding figure was less than 20 per cent despite a host of programs intended to promote mainstreaming this group.[6]

De-Institutionalization Efforts for People with Disabilities and Older Persons

Sweden was one of the first countries to adopt the concepts of normalization and integration. There is now widespread support in the country for the notion that it is society's responsibility to provide the services necessary to keep older and disabled citizens out of institutions. These measures include cash payments for general income support and benefits in kind, legislation specifying a certain level of accessibility in the construction of public and residential buildings, the provision of special transportation services as well as personal assistance. At the end of this section some recent Swedish studies will be reviewed which investigated the reasons why older persons move to nursing homes and other institutions and what measures would have been necessary in order to prevent these moves.

Cash Payments

In recognition of the fact that a disability entails higher costs of living Sweden provides monthly payments to individuals with disabilities under several programs. Eligibility is established by a physician's statement. The programs include the disability allowance referred to above which is a tax-free general income subsidy administered by the National Insurance.

Housing expenditures are subsidized by many local governments in order to increase the effective demand of persons with disabilities for better quality housing. These housing allowances are available to the general public, mainly families with children and to retired persons, and do not carry the stigma of a welfare payment, because a large segment of the population qualifies for them. The amount of this allowance is determined by a formula which takes into account the number of bedrooms, household size, income,

[3] *Ibid.*, p. 27.

[4] *Ibid.*

[5] *Ibid.*

[6] National Central Bureau of Statistics, *Disability: Participation and Equality?*, Living Conditions Report No. 25, Stockholm, 1981.

financial assets, housing costs including rent or monthly mortgage payments, and heating costs. The City of Stockholm, for example, grants an allowance to households with disabled persons in such an amount that housing costs do not exceed 22 per cent of the household's gross income adjusted for financial assets. As an example, a bachelor using an electric wheelchair for mobility with a monthly gross income of 7,900 SEK is entitled to 1,700 SEK to help him pay the rent of 2,900 SEK for his two-bedroom apartment.

Assistive Devices

Assistive devices for persons with disabilities are considered an important and cost effective part of the National Health Insurance. The major regional hospitals have a department for technical aids where occupational and physical therapists under the supervision of a rehabilitation M.D. run an exhibition of devices. Clients can try out and take home a wide variety of devices from electric toothbrushes to ceiling hoists, motorized wheelchairs, speech communicators, word processors, etc. Devices are dispensed and maintained by the hospital free of charge and regardless of income.

Accessibility in the Built Environment

Sweden was one of the first countries to adopt accessibility standards for public buildings. The legislation was extended in 1977 and now covers also residential construction both new and, less stringently, old buildings. All structures erected after 1977 of three floors and more in height must have wheelchair accessible elevators. New construction and renovation activity has, however, been low during the 1980's and the lion's share of the housing stock is still inaccessible. In Stockholm, for example, 95 per cent of the housing stock is inaccessible to wheelchair users.[7]

While general accessibility in the built environment will come about only slowly, individual adaptation of the homes of persons with disabilities is made possible by the State Housing Adaptation Grant. These funds are administered through the local governments and are commonly used for kitchen and bathroom remodeling. In some instances installation of staircase elevators has been funded. The program is applied on the basis of need and eligibility is not means-tested. If the recipient of the Housing Adaptation Grant moves to another housing unit, he or she can apply again, if modifications are necessary in order to use one's home as independently as

[7] Ratzka, A., *The Cost of Disabling Environments*, Swedish Council of Building Research, Stockholm, 1984, p. 27.

possible. Several recent empirical studies point to the important role of accessible housing in keeping older persons out of institutions.[8] Some of their findings will be discussed shortly.

Transportation

Transportation services for people with disabilities are under the responsibility of local governments. As a result there is a wide variety of solutions of differing quality and costs to consumers. Unlike the United States where disability organizations have demanded equal access as a civil right with the emphasis on accessible public transportation, Swedish municipalities and disability organizations have opted for subsidized taxi cab transportation and segregated paratransit. To give an illustration, the paratransit system in Stockholm County with a total population of some 1.2 million has a capacity of over 1,000 trips per day. The service has to be ordered at least one work day in advance. The maximum cost to the consumer per month is presently 150 SEK. (1 SEK = $0.11 in 1985) There is no limit as to the number of trips per month to persons eligible for the service. In addition, about 8,000 trips a day are made by the altogether 70,000 persons who are eligible for using subsidized cabs.[9] Subsidized cab service is open to persons who on account of physical or psychological reasons cannot use public transportation but do not need the special paratransit busses.

Travel outside one's community to other points within Sweden is made both easier and less expensive by a new state program.[10] Persons with disabilities can apply for subsidized transportation by train, air, taxi cab or paratransit, whichever way is appropriate in light of one's disability. The total cost of the trip to the user corresponds to the cost of a second-class railway ticket. The fare of a personal assistant, if required, is paid in full by the program. Eligibility is based entirely on medical need, as certified by a physician, and is not means-tested.

As far as public transportation is concerned, the underground system in Stockholm, the nation's only one, is fairly accessible to wheelchair users but no attempt has been made to make public busses and trains accessible in Sweden.

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[8] Berg, S. and Dahl, L., "Orsaker bakom flyttning till servicelagenhet, ålderdomshem och långvård" in *Två studier om boende, service och vård för äldre*, Spri, Stockholm, 1978; Malmberg, B. and Berg, S., *Äldres flyttningar till service och vård—Vetlanda 1981*, Institut for gerontologi, Jönköping, 1982 ; Thorslund, M., *Äldres flyttningar till service och vård—Sundsvall 1980*, Spri rapport 66, Stockholm, 1981.

[9] The statistics refer to the calendar year 1984 and are taken from *DHR Aktuellt Stockholm*, April 1985.

[10] Roos, B., *A National Transport System for Severely Disabled Persons—A Swedish Model*, World Rehabilitation Fund, Report #15, New York, 1982.

Personal Assistance at Work and in School

Before assistance at home, our main interest here, is taken up, a brief presentation of assistance at school and at work is provided. If integration and normalization of disabled citizens are to be achieved, personal assistance services are required to overcome the obstacles presented by all environments. Two of the most strategic situations represent school and work. Here the presence or absence of assistance often means the difference between being forced to go to segregated schools and sheltered workshops or to be able to choose education and employment according to one's aptitudes and preferences.

Children and youth with disabilities can attend their regular neighborhood schools given architecturally accessible structures and personal assistance. Since 1967 the law requires all new schools to be built accessible. Most schools erected before that date have remained inaccessible. In Stockholm, for example, 60 per cent of all primary and secondary schools are inaccessible. The rest are partially or fully accessible.

Since 1965, practical assistance is provided to disabled children and youth of school age. Under the program an assistant may accompany the student on the way to school, help him or her to the toilet, assist with lunch or take notes. Sight-impaired students get readers, deaf school children qualify for assistants trained in sign language. A student may have his own individual assistant or share one with other students, depending on the extent of the disability. Twenty per cent of all program participants in 1980 received this support during the whole school day. About 65 per cent of these children and youth had a physical disability, 8 per cent a sight and 5 per cent a hearing impairment. Eight per cent had psychological difficulties, and the rest epilepsy, minimum brain damage, autism, and social adjustment problems.[11]

To be an assistant requires no special training. About 80 per cent are under the age of 30. Many are just a few years older than the secondary students they are working for. Most assistants are housewives. The gross pay in 1980 was 5,100 SEK a month for a school day. Assistants are employed by the schools and students cannot choose who will work for them. The program's costs are shared between local and central government with the latter contributing 40 per cent. In fiscal year 1979/80 737 primary school students were covered by the program at a total of cost of 39 million SEK. The cost for secondary school students was 8.3 million SEK.[12]

There exists a similar program at the university level, the main difference being that the assistants are employed by the municipality where the university is located and all the program's costs are borne by the central

[11] Statistics on school assistants and their users from Integrationsutredning, *Personlig assistans for handikappade*, Statens Offentliga Utredningar SOU 82, Stockholm, 1981, p. 170.

[12] *Ibid.*

state. The service also assists students in obtaining adapted housing and personal assistance in the home when they have to move from their home town to a university in another part of the country. During 1978/79 costs were approximately 3.2 million SEK.[13]

What impact have these programs had on the educational integration of people with disabilities in Sweden? The official policy is to start integration already at the pre-school level. But in some communities the municipality sends a babysitter to a child's home instead of assigning him a place at the neighborhood kindergarten. A very rough indication of the extent of school integration is provided by a 1978 survey which found that 70 per cent of all students with disabilities in 9th grade attended regular classes in their neighborhood schools.[14] They were "individually integrated" to use the official jargon. The rest was divided between those who attended special classes in local schools (they were "group integrated" in the technical jargon) or went to one of the 12 state-run special schools which exist at the primary and secondary level. These institutions specialize in one particular disability and take children from all over Sweden. Their enrollment has decreased over the years as more regular schools have been made accessible and as more students have assistants.

The type of school students with disabilities attend and whether they have assistants depends to a large degree on the respective municipality. As mentioned earlier, 40 per cent of the program costs are covered by the central state. Primary education is compulsory in Sweden, secondary is not. Thus for students at the secondary level the local government is not obliged to provide assistants. Instead, many municipalities are quick to refer secondary students to one of the special state schools where all the costs including assistants are borne by the central state—even if this necessitates moving to another part of the country. The argument used by local school administrators is often that special schools have many more resources. Disability organizations, however, maintain that the social training among non-disabled peers in the regular neighborhood class room can be more important in the long run than, say, the best physical therapy.

While it is widely recognized that many students could not attend regular classes without practical help from their assistants, the program is not without critics. Some schools consider assistants as substitute teachers; students with special needs might receive less individual instruction from the teacher, if they have an assistant. Also, assistants will often do a task for the student instead of aiding the child in doing the work for him or herself. The distinction is difficult to see and to maintain for untrained personnel. Having an assistant may reduce the student's and the school's incentive for using

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[13] *Ibid.*

[14] Brattgard, S.O., Hilmerson, G., *Rörelsehindrade elever i årskurs 9*, Department of Handicap Research, Report 62, Gothenburg, 1978.

technical aids. Overprotective assistants may isolate the student from his classmates and assistants may hinder the child's development towards more independence.

Often a student with a disability receives the necessary practical aid from classmates. This solution, however, cannot be relied upon in all instances and at all times. As pointed out by teachers, the novelty of assisting a classmate with a disability may wear off and leave the child in humiliating dependency.[15]

It has been argued that the presence of an assistant emphasizes the disabled child's special status which in itself constitutes a segregative element. A possible solution may be to have the assistant assigned not to the student with a disability but to the whole class. Then he or she could also assist other students who need help, such as immigrant children who might have difficulties with the language. In this way also some of the above mentioned problems could be alleviated.

Assistance at work is a state program administered by the Swedish National Board of Labor and its local offices throughout the country. The Board has a range of policy instruments at its disposal intended to improve the disabled minority's opportunities in the labor market. Programs include medical and vocational rehabilitation, incentives to the employer in the form of wage subsidies, legal measures to force employers to hire workers with disabilities (very rarely used) as well as grants for technical aids, such as word processors, and modification of cars and work sites.[16]

A relatively new addition to this list consists of the provision of personal assistants to employees. Assistance may be in the form of practical help in getting in and out of the car, going to the toilet, for arranging heavy items on one's desk, and other aid which enables the employee to perform his or her work. Sight-impaired workers can get readers, and deaf workers are entitled to sign language interpreters under this program. The person assisting may be a janitor, a colleague or somebody from outside the firm. The assistant is employed by the same employer as the person with a disability. The employer presently receives reimbursement of the assistant's time in an amount corresponding to up to 25 per cent of a secretary's average full-time salary. Thus, the employer is not encouraged to hire persons who need more assistance than two hours a day. This program is also financed by the National Board of Labor through tax funds.

Before starting with the description and analysis of in-home personal assistance for older persons and people with disabilities, the main interest of this paper, some empirical findings are presented on the question of which services are most crucial in keeping people with disabilities out of

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[15] Integrationsutredning, *op. cit.*, p. 56.

[16] For a description of the program and some design solutions see Elmfelt, G. *et al.*, *Work Site Adaptations for Workers with Disabilities: A Handbook from Sweden*, World Rehabilitation Fund, Report #20, New York, 1983.

institutions. In the following some recent Swedish studies are briefly discussed that focus on older people who make up the majority of all persons requiring these in-home support services.

Swedish Studies on the Requirements of De-Institutionalization

During recent years several research reports have been produced that deal with the reasons why a given person enters an institution, and if so, which type of institution. The studies resemble each other in scope and approach and use samples of actual moves to institutions in five middle-sized Swedish communities,[17] and in the cities of Vetlanda[18] and Sundsvall.[19] The surveys use interviews with both staff and older persons who had moved to an institution. One of the interesting findings is that the personnel who made the decision as to whether a client was to move to an institution often knew surprisingly little about how well the individual's own home was adapted to the person's needs and how personal assistance needs were met prior to the move to the institution. In many instances, it turned out that very simple architectural modifications or assistive devices in the client's home would have enabled him or her to continue to live at home.

Another consistent finding was that staff and patients differed considerably in their perception as to what ADL tasks the patients had been able to perform prior to their institutionalization: the staff typically considered the patients as less capable than the patients themselves. Patients in an institution are not allowed to perform many tasks which are important at home. Thus the staff's judgement was not based on actual observation. In addition, given the known effects of hospitalism, ADL capabilities, especially when not maintained through practice, and self-confidence can deteriorate rapidly. One Swedish researcher found that with older persons irreversible effects of hospitalism can in some cases be observed already after only six hours of institutionalization.[20]

Bergström *et al.* investigated the consistency in the staff's decisions.[21] The staff making placement decisions, social workers and medical doctors—the clients themselves did not seem to have a say in the matter—had considerable difficulties in differentiating between the client's need for home health care, day care or old age home placement. They felt on much safer ground when they had to determine whether the client should be moved to long-term hospital care, to a psycho-geriatric ward or to internal medicine. The researchers found that the staff considered information on the client's

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[17] Berg, S. and Dahl, L., *op. cit.*

[18] Malmberg, B. and Berg, S., *op. cit.*

[19] Thorslund, M., *op. cit.*

[20] Personal communication, Göran Andersson, SPRI, Stockholm.

[21] Bergström, G. *et al.*, "Att placera äldringar i 'rätt' vårdform", *Läkartidningen*, Vol 73, No 30-31, 1976.

housing situation least important to the placement decision. Agreement was lowest on the alternative of sending the patient home supported by personal assistants.

According to one study persons moving to nursing homes had an average of 20 hours per week personal assistance in their own home prior to their move. Ten per cent of the moves could have been avoided "absolutely" or "maybe" by an increase in hours according to the staff's estimate.[22] In the city of Vetlanda 15 per cent of the moves to nursing homes were found unnecessary, "absolutely" or "maybe", if the average of five hours a week which the patients had been receiving before referral to the nursing home had been increased to 27 hours, according to the staff.[23] In the city of Sundsvall 50 per cent of the persons moving to nursing homes had personal assistance at home and 16 per cent of these individuals could have stayed at home, in the opinion of the staff, if their average hours a week had been raised from 9 to 22. Forty per cent of the persons entering nursing homes felt that they did not receive sufficient assistance at home.[24]

In general, the studies face an important methodological problem in asking staff and clients under what conditions an older person could have stayed at home longer. Faced with this hypothetical question, one is not sure whether and to what extent the respondent's answer assumes the availability of certain specified services or whether the respondent bases his or her judgement on the actual state of affairs, i.e. some of the services may not be available in the community, may be understaffed, unreliable or in danger of losing financial support in the future. (Consider the following example of a community where there is no personal assistance service after office hours and on weekends. Assume that there is an older person who would need assistance also on weekends in order to continue living in his home. Suppose now that a social worker is asked whether five more hours a week of personal assistance would enable this person to avoid moving to an institution. If the response is "no", there is no way of knowing whether the social worker considers the person unable to live at home even with assistance on weekends or whether the social worker did not think of the possibility of extending the existing service to cover weekends.) This difficulty is probably most pronounced, if the respondent has not heard of or has no actual experience with the assumed services.

This points to a major shortcoming in these studies: none of them investigated the quality of the personal assistance service that some of the movers had used in their own homes prior to institutionalization; that is, while the researchers recorded the number of hours of assistance received, they failed to ask how dependable was the service in the consumer's

[22] Berg, S. and Dahl, L., *op. cit.*, p. 17.

[23] Malmberg, B. and Berg, S., *op. cit.*, p. 80.

[24] Thorslund, M., *op. cit.*, p. 21.

perception; was it available during evenings, nights, and weekends; did the consumer have a say in who was to work for him or her, and with what tasks, at what hours? The importance of the quality of personal assistance services for consumers' ability of participating in their communities has been developed further elsewhere.[25]

While the above surveys focused on persons already in an institution, Hedenius *et al.* followed patients who were released from nursing homes to their own homes.[26] Under supervision of the regional hospital's nursing home in the city of Kalmar a considerable number of patients were able to return home with the help of personal assistants and minor housing adaptations.

Summarizing the findings of these studies, it seems that a considerable percentage of older persons now living in institutions could have stayed in their own homes, if supportive services had been available to a larger extent. The most important of these service was found to be personal assistance. Because of the methodology used in the investigations it seems that the results would have indicated even larger percentages of unnecessary moves to institutions, if the researchers had assumed improved personal assistance programs, especially services that are more flexible as to the hours of the day and week they are available.

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[25] Ratzka, A., "Hemservice i vems regi?", *Svensk handikapptidskrift*, No 9-10, 1982.

[26] Hedenius, M., Thorsell, U. and Åhlund, O., *Äldrande och boende—att återvända från långvårdsklinik*, Delegationen for Social Forskning, Rapport 1981:3, Stockholm, 1981.

III. IN-HOME PERSONAL ASSISTANCE

In-Home Personal Assistance Available to Other Groups

In-home personal assistance is available not only to persons with disabilities and older people. Most Swedish households at one time or another can apply for related programs. All of these in-home services are run by the local governments' social services office. In this respect the programs for people with disabilities and older persons are integrated with services that are available to the general public and do not carry the stigma of a welfare program. Before we discuss the in-home services for persons with disabilities, the related general programs will be briefly described.

In-home personal assistance services are available to families with children when the parents are temporarily sick or otherwise unable to care for their children. While the service is intended for shorter periods, persons with disabilities can get this help for their children on a regular basis in those communities where the service exists. In 1982 some 19,263 families received a total of 1.38 million hours or 72 hours per year per family on the average.[27]

Another group that qualifies for the service are families with sick children who normally attend day care or nursery school. The service is intended to enable their parents to get to work. Again, the service is temporary and usually very hard to get, but parents of children with disabilities can receive regular help. The service which also can be used as respite care to relieve the main providers of personal assistance may be available several hours a week, an evening or a weekend. Only a few communities have this program. More commonly, parents receive a salary from the municipality for the care of their child. In 1982 some 35,450 families received a total of 1.49 million hours or 42 hours per year and family on the average under this program.[28] This includes the hours provided by parents who were employed by their respective local government.

Finally, in-home personal assistance is available to disabled adults who need practical help in their daily lives in their own homes. At this point it might be useful to briefly outline the history of the service, because present day organization as well as shortcomings and conflicts will be easier to understand from a historical perspective.

Brief History of Swedish In-Home Personal Assistance Programs

Swedish in-home personal assistance programs date back to the beginning of the century when such services were established as small and informal mutual insurance schemes at the neighborhood level or were

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[27] National Central Bureau of Statistics, *The Home-Help Service during 1982 and Assistance Given in the Home or Other Facilities for the Aged and Handicapped on 31st December 1982 and Week 43, 1982*, Statistical Report SCB S1983:14, Stockholm, 1983, p. 1.

[28] *Ibid.*

organized by the incipient labor movement along the lines of trade membership. These schemes were primarily intended to provide temporary relief to the family in case of the mother's illness.

With the the Social Democratic Party's rise to power in the 1930's, local governments took over the programs and expanded them. Now the service was geared more to serve older people in order to free their children—usually the daughters—from part of the responsibility of caring for their aging parents and to enable them to enter the labor market. The service was probably not meant to support senior citizens with extensive needs who lived by themselves without nearby relatives. Nor was support on a long-term basis intended. For such cases a growing number of public old-age homes were built.

During the next decades both in-home personal assistance services and institutions for older people increased in number, as the country's growing industrialization with its demand on the labor force's geographical mobility made it increasingly difficult for extended families to exist. Today the institutional solution has come under cross-fire. Although old-age homes are now being replaced by the less institutional "service houses",[29] older people demand more integrated housing solutions in the regular housing stock. In light of the skyrocketing costs of institutional care and the rapidly increasing population of older people these demands are beginning to receive general support.

The 1980's have been characterized by a willingness on the part of local governments to experiment with new types of in-home support services which would enable senior citizens to remain in the regular housing stock much longer than it has been possible up to now. Such services include a flexible cooperation between municipalities and county councils (responsible for health services) where regular personal assistance is supplemented by visiting medical staff as needed. Experimentation is also under way in the area of housing rehabilitation with the accessibility needs of people with disabilities in mind. Noteworthy here are accessibility legislation for new and existing structures, novel technical solutions for retrofitting existing walk-up housing with elevators, and state subsidies for their installation.[30] There is an interest among health care planners in methods of delivering even advanced

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[29] Service houses, the successors of old age homes in Sweden, are occupied exclusively by elderly persons who live in their own apartments and have access to leisure time activities and personal assistance on the premises. The buildings are owned and operated by the respective municipality. Admissions and eligibility are handled by the city's Social Service Office. Tenants have regular rental agreements.

[30] For a description of some of these services and technical solutions, their costs and probable impact on de-institutionalization see Ratzka, A., *The Costs of Disabling Environments*, National Concil of Building Research, Stockholm, 1984.

medical treatment in one's home with all the requirements such an approach would entail in terms of architecture, medical equipment, staffing, and organizational solutions.

As this very rough outline of the history of Swedish personal assistance programs shows, the services were intended primarily for older persons whose functional disabilities were not too extensive. Individuals of any age with more severe limitations—if they were able to survive in the first place—could not exist outside of institutions. When in the 1950's and 1960's the concepts of normalization and integration began to win ground, the groups that were able to leave hospitals and other institutions (or avoid them) were primarily those individuals who could benefit from advances in medical rehabilitation to such a degree that they were not dependent on personal assistance in their daily life. In Sweden today, persons with extensive assistance needs without the support of a family still have difficulties in obtaining services which would enable them to live independently in the community. For most of them semi-institutional cluster housing is the only alternative.

The reasons why Swedish personal assistance schemes are not geared to support independent life styles of individuals with more extensive disabilities can be found in the organization of present personal assistance services which has not changed materially since the 1930's. Service delivery has not been adapted to the needs of this relatively new consumer group who today can stay alive due to the medical and technological advancements of the last decades. Furthermore, the professional and hierarchically structured organization from the 1930's has not been modified to keep up with changing consumer demands for more flexibility and consumer control which would allow a self-directed, active life style in the community.

It is interesting to note that it was in California, Denmark and England that ventilator dependent post-polio patients left the hospital wards first. The primary reasons were not that these places had superior medical attention—California, Denmark, and England also were the first to start personal assistance schemes that were designed specifically for the extensive needs of these former patients.[11] In the case of California and Denmark consumers were given the choice to become formal employers of their assistants which entails the maximum control over service delivery. This approach is in recognition of the fact that the more extensive one's need of assistance, the more important it is for the consumer to design his or her own system. In countries without such extensive and consumer-controlled personal

[11] For information on California and England (St. Thomas Hospital, London) see Laurie, G., *Housing and Home Services for the Disabled*, Harper and Row, New York, 1977. For information on Denmark see Ann Isberg's paper presented at the Third International Polio and Independent Living Conference, St. Louis, Missouri, May 1985.

assistance programs such as Sweden it took these groups much longer until they could leave hospital wards and nursing homes.

As an aside, the exodus of post-polio patients from their hospital wards in California in 1959 that was made possible by the introduction of the State In-Home Support Service can be considered the beginning of the Independent Living Movement in the United States. The service as well as the independent living skills that these ex-patients acquired by hiring, training, and firing their own personal assistants enabled many of them to become community organizers and disability rights advocates. This may be the reason why in the US many of the most prominent disability leaders are individuals with extensive disabilities. In Sweden, on the other hand, people with disabilities—not to speak of those with more extensive disabilities—are often in the minority in elected offices and staff positions in their own organizations. The explanation, then, why consumer control in personal assistance services has not been an issue for Swedish disability advocates might simply be that they often do not need personal assistance!

Description and Analysis of In-Home Personal Assistance Programs

User Statistics

The available statistics indicate that the program caters mainly to older people. More than two thirds of all users are senior citizens. In fact, twenty per cent of all persons of 65 years and older and 43 per cent of all Swedes above 79 are users of the service. In 1982 a total of 330,000 persons or 4.12 per cent of the total Swedish population received altogether 56.6 million hours or 172 hours a year on the average.[32] The average number of hours per person is 3.3 per week with wide variations, from two hours every other week for house cleaning up to several hours a day. Yet more than 30 to 40 hours a week are rare.[33] In many communities personal assistants are not available after office hours and during weekends with severe implications for those persons who need this service seven days a week day and night.

The contention was made earlier that compared to, say, California's In-Home Supportive Services Swedish personal assistance was more oriented to older persons who need few hours than to persons requiring extensive assistance. The annual average cost of the service per person served by the program in Sweden was 10,300 SEK in 1982.[34] In California the corresponding figure for fiscal year 1983/1984 is $3,100[35] which implies almost three times as many hours.

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[32] National Central Bureau of Statistics, *op. cit.*

[33] *Ibid.*

[34] *Ibid.*

[35] Zukas, H., Cone, K., Leon, J., *Descriptive Analysis of the In-Home Supportive Services Program in California*, World Institute on Disability, Berkeley, 1985, p. 1.

Administration

In-home personal assistance programs are administered by the municipal social service office at the neighborhood level. By way of an example for the organization of the services, the City of Stockholm is divided into 18 social service districts. Each district serves 20 to 30 thousand inhabitants. Each district, in turn, consists of one to two dozen subdistricts. The various social services including personal assistance are coordinated by social workers at the district office who dispatch assistants to consumers in their respective subdistricts. In this way social workers who also are supposed to make periodic home visits and assistants gain familiarity with their clientele.

Needs Assessment

The need in terms of the number of hours of assistance is assessed by a social worker at the district office of the municipal Social Services Office. The office is also responsible for case finding. In addition, hospital staff and other public and private agencies that might have contact with persons in need of the service commonly refer their clients to the program. Personal assistance services are well-known by the general public and lack of information about the availability is seldom a reason why a person in need of the program does not receive the service—with the possible exception of the growing population of older persons among immigrants.

To the knowledge of this writer, no formal operational guidelines, as used for example in California*, exist in Sweden for determining the extent of an individual's assistance needs. Social workers who are responsible for assessing needs will point out that their directives are to take a person's whole life situation into account including such circumstances as family situation, housing arrangement, and life style. Apart from regional inequalities in the provision of these services, there are indications that even within a given municipality the number of hours granted varies among individuals with the same apparent needs.[7]

Home help for people with disabilities might consist of assistance in getting up, getting dressed, personal hygiene, cooking, shopping and running errands, house cleaning, taking walks, and similar tasks. In some cases, older persons living by themselves without actual need of personal assistance will be offered a few weekly hours as a preventive measure. Through the regular contacts health problems can be monitored and counteracted but, equally important, the need for moving to a service house or other institution merely out of loneliness is reduced. This psychological problem is receiving increasing attention. One of its expression can be

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* See for example, *In-Home Supportive Services Needs Assessment*, Social Services Agency, County of Alameda, 401 Broadway, Oakland, California 94607.

[7] Personal communication, Ellen Sääf-Bergström, Stockholm Office of Social Services.

insecurity and fear of emergency situations. In that case a mechanical device such as the emergency call system described in one of the next sections will be of no real help. Recently the Social Service Office in Stockholm has taken the initiative of organizing small neighborhood groups of senior citizens. The way the groups start is that the assistants who usually work for a number of consumers will invite all their clients together to an afternoon coffee hour in one of the clients' home. After a few introductory get-to-gethers the senior citizens are expected to continue and expand this contact informally on their own.

Assistants

Between 80-90 per cent of the assistants are female, usually middle-aged housewives who choose working hours that suit their families. Four per cent are full-time employed, 51 per cent work regular part-time schedules, the remaining 45 per cent work on an hourly basis as needed. About fourteen per cent of all home help assistants are relatives who are employed by the city to work for spouses, parents or children who have disabilities.[8] Assistants are paid the lowest municipal wage, presently 38 SEK an hour. Of the 70,000 assistants who worked in Sweden during 1980 about 30 per cent had received some training, usually a two-week course.[9] The question of workers' training will be taken up again below.

Costs

The municipal in-home programs' costs are shared between local governments and central state. The latter contributes 35 per cent of the costs. Despite some control over the enforcement of the pertinent regulations by the National Board of Welfare, decisions on type and quality of service rest to a large degree with the local governments. As a consequence there are wide regional variations in service delivery depending on local government finances and political majority in the city council.

In 1982 expenditures for the service on the national level amounted to a total of 3,963 million SEK.[10] This figure corresponds to about $445 million at the 1985 exchange rate. Divided by the total Swedish population the amount is 477 SEK or $54 per capita. These statistics demonstrate the wide acceptance and the broad political base for the service among the Swedish people. For comparison, in fiscal year 1983/84 expenditures for California's In-Home Supportive Services, the oldest and one of the most extensive programs in the United States, came to a total of $297 million which amounts to $12 per capita, if divided by the total population.[11]

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[8] National Central Bureau of Statistics, *op. cit.*, p.18.

[9] *Ibid.*

[10] *Ibid.*

[11] Zukas, H., Cone, K., Leon, J., *op. cit.*, p. 1.

The cost of the service to users varies widely among municipalities. In a few communities the service is free. In others, fees are charged per hour with a maximum monthly amount. The ceiling is often means-tested and may go up to 800 SEK a month in some cities. In other schemes all users pay the same flat fee regardless of the number of hours of service rendered. In line with the stagnating Swedish economy during the 1980's local government finances are strained with the result that consumers' fees are on the increase throughout the country.

County Home Health Services

Where disability is accompanied by chronic medical conditions or where assistance is required during the night, the responsibility for that part of the service rests with the counties. In some counties, persons with such needs and without support from their families will be offered a bed in a nursing home, since no programs exist which can deliver that type of assistance.

In other counties assistance outside regular working hours is delivered by the municipal home help staff, complemented by a visiting nurse where necessary, and the cost is borne by the county. In some communities the county sends its own staff, usually nurses' aides, to one's home for the more medically oriented tasks while municipal home help assistants take care of the non-medical personal and domestic chores. The solution seems awkward. Besides the obvious difficulties in defining tasks and coordinating the two agencies' staff, consumers complain about the constant flow of different people through their home disturbing their privacy. The distinction between non-medical and medical tasks is not uniform throughout the country. Some local governments—they tend to be characterized by high income, low tax rates and conservative rule in the city council—will define personal tasks such as helping the consumer getting dressed in the morning as medical in nature. The pay-off to these municipalities of this "medicalization" of personal assistance are lower expenditures, since the county is responsible for medical tasks.

In several counties cash payments are made directly to the consumer who turns over the money to his or her family or a person living in the home. (This practice is called "object employment", the worker is employed to work only for one person, the "object", as opposed to working in the regular municipal home help force where assistants work for any consumers they are assigned to.) In 1982 there were about 2,000 persons who received between 200 and 1,200 SEK per month tax-free from their county for working for a household member.[6] To put this amount into perspective, 38 SEK is presently the lowest municipal hourly wage. In a few undocumented instances some

[6] Daatland, S.O. and Sundström, G., *Gammal i Norden. Boende, omsorg och service 1965-1982*, NORD, Oslo and Stockholm,1985, p. 71.

counties pay market wages to the family members who care for the "patients", as the consumers are called under this scheme.[4]

Escort Service

Swedish communities by law have to provide paratransit services. In contrast to other countries, such as the United States, no effort has been made to make public transportation accessible. Usually there is door-to-door service and the user is assisted in negotiating architectural barriers such as steps. Yet many will need more assistance when outside their home. Recognizing this need a few municipalities have recently started escort services.

The escort is a municipal employee who is usually already working for the social service office as an attendant and who accompanies and assists the consumer while shopping or pursuing a leisure time activity outside the home. In Stockholm, for example, users of the regular home help service with more extensive functional disabilities are eligible and entitled to 15 hours of service per month for a maximum of three outings at five hours each. The service is considered a complement to the regular home help and there is no additional cost to the consumer. The escort service has to be applied for several working days in advance. While the service recognizes an important need, some users criticize the fact that they have no control over who will accompany them on an outing and that there is no room for spontaneous decisions. Some consumers refuse to utilize the program and prefer to make their own arrangements with people they know.

Evening Patrols

Swedish central and local governments have adopted the aim of supporting the disabled and elderly population in staying out of institutions as long as possible. The belief in the higher quality of life in the community has been aided by the now widely accepted cost advantages—especially in the light of the predicted continued growth in the population of older persons.

As already noted, in many communities municipal personal assistance is not available after office hours or on weekends. Thus persons in need of more extensive assistance who cannot rely on relatives or cannot afford to pay workers out of their own pocket have to move to an institution. During the last few years several cities have begun to remedy this situation by providing services under a program called "evening patrols". The service consists of teams of two municipal employees each who travel by car or taxi from one consumer to the next according to a pre-arranged schedule. The patrol assists with going to bed and preparing for the night.

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[4] *Ibid.*

So far the service has been adopted by some cities on an experimental basis, mainly for older persons. The program has been criticized by younger consumers who point out that it is inflexible and unreliable, since a delay at one point in the schedule will affect all subsequent users. The common criticism, which applies to most Swedish personal assistance programs, is that consumers have no control over the staffing of this service and often will not know who will work for them on a given day. Also, recent articles on personal assistance in the daily newspapers took up the disadvantages of the service citing the example of an older man in Stockholm who has to go to bed at 5 p.m. every day of the year—even during summer when the sun is up until 10 p.m.[44]

Emergency Call Systems

Another development intended to decrease the need for institutions consists of installing devices in the user's home through which assistance can be summoned. Senior citizens who live by themselves but also younger individuals often express their fear of an unforeseen emergency which would leave them helpless and unable to call for assistance. This insecurity is a reason why many older persons without actual functional disabilities move to institutions.

There are various devices and organizational solutions which can be grouped into so-called active and passive systems. One active system, for example, is a small wrist watch-sized transmitter which allows the user to communicate with a manned staff room via microphones and loudspeakers set up at strategic points in the user's home. An example for passive systems might be one where a municipal employee makes periodic phone calls to check whether the user is well. Another example is a device installed in the user's home that automatically triggers off an alarm in a staff room, if no electrical appliance in the home is used for a predetermined number of hours.

Over 6,000 apartments in Sweden are connected to active systems and 900 which are hooked up to passive systems.[45] The experience with these emergency systems so far is inconclusive; many older persons do not feel safe with these devices and prefer human contact. A recurrent comment on the part of municipal administrators is that technical solutions can substitute for staff to only a certain degree and that the organizational arrangement of who will respond to an emergency call is of paramount importance.

The apartments connected to a staff room via an emergency call system are either located within or in close proximity to service houses.[46] As more people living in the regular housing stock are to have access to emergency call

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[44] *Dagens Nyheter*, October 10 through 19, 1984.

[45] National Central Bureau of Statistics, *op. cit.*, p.18.

[46] For a description of these segregated housing and service facilities see footnote 29.

systems, other solutions as to the geographical location of staff rooms and organizational arrangements have to be developed.

Fokus or Cluster Housing

Cluster housing under the name of Fokus housing is internationally the best known Swedish effort for keeping people with extensive need of personal assistance out of institutions. This solution has been in existence in Sweden for more than 15 years. The concept was first realized by the Fokus Society under Prof. Brattgard in the late 1960's.[6] The original 280 Fokus apartments are located in 12 Swedish cities. The common pattern consists of 10-15 special apartments dispersed throughout one large apartment complex of perhaps 50 or more units. In this sense the tenants with disabilities are geographically integrated. Fokus apartments are designed for the accessibility needs of wheelchair users. The units are connnected via intercom to a staff on duty 24-hours a day. In the original concept the apartments were mainly intended as a half-way house solution. Individuals with extensive disabilities coming from parental homes or institutions could in these units acquire the skills necessary for a life in regular housing.

Through the political efforts of the Swedish disability organizations and the Fokus Society Swedish local governments in 1973 were charged with the legal responsibility of providing that type of housing and services. Since that date all Fokus units are operated and financed by the respective municipality they are located in. Up to 1985 an additional 720 apartments have been built throughout the country that differ somewhat from the original Fokus concept. Cluster housing is no longer referred to as Fokus but as "boendeservice" which might be translated as "housing with service". To the disability organizations that propagate for more *boendeservice* apartments the term "Fokus" has institutional connotations and they claim that there are significant differences. *Boendeservice* in contrast to Fokus apartments do not share common bathing, laundry, kitchen, and dining facilities. The units consist of fewer apartments now ranging from 5 to 10 instead of 10 to 15. This decrease in numbers was to further improve the geographical integration of the units in the neighborhood and to avoid any resemblence to an institution. The basic principle, 24-hour access to staff from a nearby common staff room, remains the same.

In Stockholm *boendeservice* apartments are built and operated by municipally owned housing companies within the regular housing stock. The additional construction costs of the units due to their larger-than-standard floor plan, estimated at an average of 90,000 SEK per apartment, are covered

[6] Brattgard, S.O., Carlsson, F., Sandin, A., *Housing and Service for the Handicapped in Sweden*, The Fokus Society, Gothenburg,1972.

by the State Housing Adaptation Grant mentioned earlier.[**] The staff based in a large apartment within the apartment complex is under the direction of the home help service of the city's Social Service Office. The cost of the service to the consumer is means-tested but does not presently exceed 440 SEK a month. The tenants of the *boendeservice* units are selected by the city's Social Service Office who also leases the apartments to the tenants.

Despite the 15 year old history of cluster housing in Sweden little has been done in the way of critical evaluation. This fact can in part be explained by the overwhelming lack of independent living housing alternatives; as long as for many individuals a bed in a nursing home is the only housing alternative, consumer organizations, service providers, and researchers seem to be less inclined to critically analyze and evaluate *boendeservice's* limitations.

Though most of the residents seem satisfied with their living situation, frequent dissatisfaction is voiced in private. Complaints about the high turnover among the staff, the frequent changes of workers whom a resident is exposed to, and the limited input in the decision of who is to assist a given tenant are similar to those raised by individuals who use the regular municipal personal assistance service in their homes outside of cluster housing settings.

Among the shortcomings specific to the cluster housing solution, as cited by residents, is the possibility that assistants can be summoned to work for another resident whose momentary needs are considered more pressing. The urgency of tenants' needs is assessed by the staff. Thus, during morning hours the staff can seldom stay during one tenant's entire routine without interruptions (especially, if some workers have called in sick and no substitutes have been found which happens quite often). Such interruptions can cause considerable delays and as a result, residents find it difficult to plan their day. Since staff members are often forced to set priorities in how to allocate their limited time among the residents' competing needs, tenants have developed individual coping strategies. With time many residents have learned to assess the probabilities of receiving assistance for various tasks at a given time of the day and week and to adjust their needs to the staff's schedule. Another response is to try to gain a competitive edge over fellow residents by developing a pleasing, non-offending attitude towards the staff.

There are recent developments which point to future changes in the *boendeservice* scheme and its prominent position among Swedish housing alternatives. During the last few years some of the residents with more extensive disabilities in Stockholm's older cluster housing units have successfully negotiated for their own personal attendants who are not

[**] Personal communication Gunilla Wahlström, anpassningsgruppen (housing adaptation group), Fastighetskontoret (Department of Real Estate), City of Stockholm, October 26, 1984.

connected to the unit and who come in the mornings for the entire morning routine. During the rest of the day these residents rely on workers from the central staff room as before. Residents who managed to get these personal assistants reportedly experience the change as a significant improvement in their quality of life. They report increased self-confidence gained from a feeling of being in charge and able to plan their day. It would seem that these persons could move out of their cluster housing unit, if they managed to develop a satisfactory back-up and emergency system.

A handful of consumers in Stockholm and neighboring communities have gone a step further. They live in regular housing and recruit, train, and schedule their own assistants. The workers are employed by the municipal Social Service Office who administers payment of wages, tax withholding, and all other employer's tasks. The solution has not received any publicity. Consumers with such arrangements have been reluctant to talk about it, apparently out of the unfounded fear that the solution is not completely legal and might be taken away from them, if the news would spread.

Social workers have not made any attempts to encourage their clients to find their own assistants. One reason might be that it is the social worker's job to perform these functions and the thought of informing clients of the possibility of finding their own assistants might not have occurred to them. There are also institutional hinders to this solution. Most consumers who have such arrangements need part-time workers, since they do not have enough hours for the 8-hour shifts of full-time assistants. Part-time work, however, is not looked upon favorably by the unions who demand full-time positions in their drive to upgrade the status of workers. Social services offices are reluctant to put new part-time workers on the payroll also for economic reasons, because they have to first find work for their full-time employees who receive fixed monthly salaries regardless of the number of hours worked. Further, some social workers when asked about this solution do not see any advantage for the consumer in it. They will also point out that in their opinion only very few of their clients have an interest in or would be capable of running such a system.

Assessment of Personal Assistance Services

Administrative Compartmentalization of Personal Assistance Service

Conceptually, personal assistance services consist of practical help with all the tasks which consumers cannot perform by themselves due to their disability. These tasks may range from getting up in the morning and needing assistance with bathing, toiletting, and dressing to household chores such as cleaning, shopping and preparing meals. Similar help might be required at work, in school or wherever else one may be. Assistance might be needed

with transportation, moving about town, making phone calls or running errands. Depending upon the nature of the disability a reader or sign language interpreter may be required.

While consumers may not see a difference between the need for practical help, say, in getting to the toilet at home and at work, in Sweden the responsibility for funding, administration, and recruitment of workers in the two situations will be entirely different. Assistants at work are under the jurisdiction of the local offices of the State Board of Labor Market, whereas in-home support is the responsibility of local governments. In some communities, as mentioned above, a difference is made between household chores (under the responsibility of local governments) and personal hygiene (sometimes considered a medical task and as such the charge of the respective County Council). Consumers eligible for the escort service have to apply to a special section within the municipal Social Service Office. If they cannot use public transportation for that occasion, they also have to order the paratransit service at the County Council's paratransit office. The escort or any other municipal worker for that matter is not permitted to drive the consumer in the consumer's car.

To the consumer the compartmentalization of personal assistance services has severe consequences. For one, the agencies involved have their own eligibility criteria and periodic eligibility checks; they answer telephone calls only during certain hours of the day; services have to be ordered at least one and sometimes several work days in advance. Thus, the individual consumer has to spend quite a number of hours each month in handling these contacts. Consumers who do not have the time or energy required for these adminstrative tasks or do not have the capability or possibility to plan their life so far in advance, for example for health reasons, cannot utilize the services to the degree they would need them.

Consumers are often dependent on not only one but several services. With each additional service used, the probability of delays or breakdowns in the total system increases rapidly as problems can arise in any link of the chain. At a recent conference on housing and services for people with disabilities in Stockholm the national chairperson of a Swedish disability organization told the audience that during the previous week she had lost two days of work. Her cluster housing facility had been short of staff and when the paratransit driver arrived to pick her up to work she was still in bed. The transportation service that has to be ordered at least one day in advance could not wait for her. The example illustrates the vulnerability of the consumer who is dependent on the smooth interaction of services provided by several agencies. Regarding our example, to many consumers the ideal solution would be that the worker who assists them with their morning routine also drives them to work. Since this arrangement would be

considerably less expensive than the paratransit service, the solution would even allow subsidization of the consumers' use of their own car and still be advantageous to the tax payer.

The most far-reaching consequence of the fragmentation of services is the sense of alienation and powerlessness which the division of responsibility for the programs breeds in consumers. Of all services which determine the consumer's quality of life personal assistance is probably the single most important one. To split up personal assistance into many different compartments over which the individual has no control may make it difficult for the consumer to see his or her life as a unity. Under such circumstances it is difficult to perceive oneself in charge of one's life.

Economics of and Obstacles to De-Institutionalization

In Sweden one of the expressed aims of assisting older people and persons with disabilities in their homes is to reduce the demand for costly institutional care. A bed in a long-term ward excluding food and medically related expenses cost approximately 480 SEK a day in 1982.[29] This cost consists mainly of labor costs for personal assistance and capital costs for the physical plant. In comparison, the cost of one hour home assistance to Stockholm City was 60 SEK including all employer's costs and administrative expenses.[30] Thus, compared to the most expensive institutional alternative it pays to provide home assistance, as long as the need does not exceed approximately eight hours a day.

This admittedly rough calculation nevertheless reflects some of the economics involved. Administrators are quick to point out that it is a person's whole life situation and not economic considerations which will determine where a particular individual will end up living. The irony is, however, that many more individuals with disabilities—among them individuals in their twenties—as well as older people could leave hospital wards and other costly institutions, if planners would follow the economic criterion. The number of persons presently put up in nursing homes who could live in their own home with several hours assistance a day has been estimated at 7,000 in Sweden.[31]

There are several reasons for this obvious waste of human and monetary capital. As has been pointed out already, in many communities the services available cannot support persons who need personal assistance outside regular office hours. Often, it seems, the relationship between insufficient

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[29] Ratzka, A., *op. cit.*, p. 61.

[30] *Ibid.* Rent or capital costs do not have to be added to the at-home alternative, since moving to the institution does not always free the patient's former housing unit; there might be a spouse or other household member who continues to occupy the apartment. Most people upon moving to a nursing home do not want to consider this move as final and try to keep their old housing for several years.

[31] "Boendeservice i varje kommun", *Svensk handikapptidskrift*, Vol 58, No 9-10, Oct. 1981, p. 21.

in-home personal assistance and the resulting need for institutional care is not properly understood by planners in the respective government agencies. Such an understanding would require closer cooperation between various levels of government. There are, however, obstacles to such cooperation: In-home assistance is paid by the city, hospital care by the county. Politicians at the municipal level are not willing to suggest a raise in local taxes to finance a larger municipal assistance program—a program which would save money for the county. Only a few counties have started subsidizing municpal in-home support services.

Another reason why many persons cannot leave insitutions or have to move to institutions is the shortage of accessible housing. While legislation requires wheelchair accessibility for all new residential construction and, considerably less stringently, for renovated older structures, the number of accessible units is still severely limited. In Stockholm, for example, 95 per cent of all housing is inaccessible to wheelchair users.[12] Thus, the probability that a person who acquires a disability is already living in an accessible structure is small. Moving to a newer and accessible building is made difficult and time consuming by the tight housing market in the larger cities. Recently, central and local government subsidies have become available that cut in half the owner's cost of retrofitting multi-family structures with elevators. Unlike the State Housing Adaptation Grant mentioned earlier, these subsidies are available regardless of whether any persons with disabilities are presently occupying any of the apartments in a given building. Apartments are the prevailing form of housing in Swedish cities. Since lack of elevators is one of the most important reasons why people with disabilities have limited choices in the housing market, the program holds great promise for allowing people to stay in their own home when they become disabled. At the present, the subsidy program is still too new to have any significant impact on current de-institutionalization efforts.

Professionalism and Limited Consumer Input

Swedish personal assistance programs and social services in general are characterized by a trend towards professionalization. The unions are on record for pushing for upgrading of assistants' status and an important aim is full-time employment. While in 1980 only four per cent of all Swedish municipal personal assistants were employed full-time, in 1982 this figure was already seven per cent and can be expected to continue to rise. At the same time the number of persons who are employed by the municipality in order to work for a disabled member of their family, living in their household or not, has been decreasing from 24 per cent of all workers in 1970 to 14 per cent in 1982.[13] According to one observer, there are municipalities where

[12] Ratzka, A., *op. cit.*, p. 27.

[13] Daatland, S.O. and Sundström, G., *op. cit.*, p. 68.

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today not a single assistant works for a relative.[5] This trend has been ascribed to efforts on the part of unions and local governments to upgrade the professional status of their staff.[6]

It would seem that an increase in full-time employment will limit the total number of employees. In particular, work opportunities for students and other typical part-time workers will decrease. Many younger consumers of personal assistance prefer the flexibility in working hours and attitudes that often characterizes these workers.

Another step towards more professionalism among personal assistants consists of the demands by the unions and the organizations of people with disabilities for more workers' training. The unions expect higher status and, ultimately, better pay (although at present more training is not rewarded by higher wages). The large disability organizations support these demands in the hope for better quality service.

A straightforward way of improving the quality of the service would seem to be to raise workers' wages; more applicants would compete for a given number of positions and selection criteria could be raised. The problem remains of whose criteria would be used. For personnel adminstrators at the municipal social services office formal qualifications such as health care related courses and work experience in institutional settings are important selection criteria. Yet such qualifications are questioned by many experienced users of personal assistance who live outside of institutions. Younger consumers will point out that the courses offered by local governments are geared towards assisting older persons who make up the majority of all consumers of personal assistance. This training, it is claimed, instills attitudes in the workers towards their clientele which younger consumers find negative. The same goes for work experience in institutions. Signs of attitudes that do not support a sense of self-direction and self-worth among consumers can be found in some of the language around personal assistance. In many regions workers, for example, are commonly referred to as "home samaritans". The Good Samaritan, according to the biblical account, saved a half-dead, robber victim whom he happened to see at the wayside from a certain death. Thus the term seems to imply that the consumers' life and well-being is completely dependent on the charitable instinct of some chance passers-by. Further, the work of the "home samaritans" is commonly called "vård", "omsorg" or "att ta hand om"—terms that suggest passive dependence and being taken care of. The view of people with disabilities conveyed in this language is incompatible with the goal of full participation and equality.

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[5] *Ibid.*

[6] *Ibid.*

Many users of personal assistance feel that the less institutional work experience and health care-related training assistants have, not to speak of courses in disability psychology offered by some social service offices to their workers, the easier it is for the consumer to direct his or her assistants. If somebody is to be trained, many consumers contend, it should be the users of personal assistance. To motivate and direct another person takes some psychological and educational skills which have to be learned. Besides, the turnover rate among assistants, about 30 per cent per year in Stockholm,[17] is much higher than among consumers which makes investments in users' training more meaningful. Innovative and successful methods for training consumers are available.[18]

As a selection criterion, then, many consumers would suggest actual job performance. Since personnel administrators, however, seldom have the opportunity to observe workers in the home of consumers, the performance evaluation would have to be done by the individual consumer. Such an approach as well as the notion that it should be the consumer who trains and supervises his or her assistants is, however, contrary to the aim of upgrading workers' professional status.

The move towards higher forms of professionalism finds another expression in the recent introduction of assistant teams. In Stockholm, for example, in several districts assistants work in groups of four to five. Each morning the team starts the day by meeting in their staff room, usually an apartment rented by the city's social service office in the neighborhood of the team's clients. During these morning meetings workers discuss and distribute among themselves the tasks for the day. The rationale for this innovation is to improve the assistants' working conditions by providing them with a place of their own for meetings, meals, and support from their colleagues.

The solution has not gained popularity among consumers for the following reasons. For one, staff meetings at 8 a.m. for 20 minutes or more mean that consumers cannot start their morning routine before 8:30 a.m. which is too late for people who work or have children. Also, some consumers fear that when assistants discuss their work load with each other, details of the clients' private lives will be exchanged. About 20 to 30 per cent of the assistants' working hours are spent on activities such as staff meetings, training, travelling to consumers' homes, and rest periods.[19]

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[17] Personal communication, Gerdt Sundström, Department of Gerontology, University of Jönköping.

[18] One of the main services offered by Independent Living Programs in the US are Independent Living Skills Classes. See for example, Saxton, M., "Peer Counseling", in Crewe, N. M., Zola, Irving K. and Associates, *Independent Living for Physically Disabled People*, Jossey-Bass Publishers, San Francisco, 1983.

[19] Personal communication, Gerdt Sundström.

Another example of professionalism are tasks of therapeutic nature which the Social Service Office charges the workers with. Thus, assistants are to "activate" consumers. To "activate" usually means that assistants are to perform only those tasks which the consumer cannot do himself or herself. In a recent report on the quality of personal assistance in Stockholm conducted by a disability organization a common example of this approach was cited. Workers will dust off the upper corners of pictures on the wall and motivate consumers to do the lower corners which are in reach for a seated person.[40] To many consumers the issue in using assistants is not only that they need help in getting chores done which they cannot do themselves; many tasks which the consumer might be able to perform himself will take much time and energy which can be spent on other activities, say, employment. The choice as to how to spend their energies, consumers contend, should be theirs. A similar expression for what might be termed paternalism is a recent decision by the Stockholm Social Service Office that prohibits attendants from buying alcoholic beverages for their clients.

A list of regulations governs the various tasks which assistants are allowed to perform in a consumer's home. For example, in Stockholm a worker is to clean only the consumer's bedroom, bathroom, kitchen and living room but no other area. Linen or carpets may not be laundered. No windows above the ground floor may be washed for safety reasons. For many consumers house cleaning is done every other week on a fixed day regardless of unscheduled needs. There is much uncertainty around these written and unwritten rules which tends to cause confusion and insecurity among users of the service.

The regulations not only limit the type of tasks which the workers may perform, they also specify the assistants' working conditions. The consumer's home is somebody else's work site. Thus, a supervisor at the city's Social Service Office may inspect the consumer's home in order to check, for example, whether the bed is of the right height and accessible from at least three sides. The regulations are the result of periodic negotiations between the city administration and the labor unions. Individual consumers or their organizations have no part in these decisions.

The area where the lack of consumer input is felt most is the decision of who will work for a particular user of the service. Many consumers will contend that the work consists of very intimate moments and constitutes a close social relationship during a large part of the day. Also, the consumer, by the nature of the work, is forced to expose his or her everyday life and private sphere to another person. Under these circumstances having an outsider, a social worker at the local Social Service Office, decide who will work for a particular consumer can be experienced as a humiliation. The assumption

[40] Nordström, M. and Örn, G., *Studie över hemservice för handikappade*, HCK Stockholms län, 1984, p. 27

that any assistant can work for any person, the explicit rule especially in cluster housing units, amounts to a denial of an individual's uniqueness as a human being. Implied in this rule is the attitude that all people with disabilities are the same, as if their disability was the only important aspect of their person. (This stereotypying mechanism when applied to other groups, to a different race or sex, for example, is commonly called racism or sexism and considered a form of discrimination. When directed against people with disabilities the Independent Living Movement refers to this attitude as "handicappism".) As one consumer, a woman, stated at a recent conference on cluster housing, "it is only after I moved to boendeservice that I no longer have control over which men enter my bedroom"[5]

A repeated complaint by consumers is that social workers, out of an alleged misunderstood professionalism, will see to it that no personal attachment develops between client and worker. For that reason consumers often hesitate to indicate a preference for particular workers, since they fear that as a result other workers will be assigned to them.

There is also a very tangible and practical aspect to this issue. Individuals with extensive disabilities have specialized needs that differ from person to person. Each time a new worker comes, he or she has to be instructed and trained by the consumer in work routines that might be unique to a particular consumer. In this way a morning routine that will take, say, three hours with a trained worker might take up to one or two hours more. Apart from the aggravation and inconvenience of being awakened by a stranger who has to be instructed, the delay will affect the consumer's ability of leaving for work at the scheduled hour. Since turn-over among the municipal employees is very high—one consumer in Stockholm is on record as having had 67 different workers within a single month[6]—the uncertainty about at what hour a person will be able to leave his or her home in the morning might be a contributing factor to the high unemployment rate among persons with extensive needs of personal assistance in Sweden.

To workers the presently high turnover rate and resulting frequent changes in assignments are not satisfactory either. They often report discomfort when they are sent to new and unknown persons whom they have to assist with intimate tasks such as personal hygiene.

In summary, there is a clear conflict between workers' attempts to upgrade the professional status of their work and consumers' interests in obtaining more control over service delivery and quality. The question then is how both quality of personal assistance and worker satisfaction can be improved without turning the work into a profession.

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[5] Conference on *boendeservice* organized by Stockholms kommunala handikapprad (municipal council on disability issues), Almåsa kursgård, Stockholm, January 28, 1985.

[6] Personal communication, STIL (Stockholm Independent Living group).

Decentralized Financial Responsibility and Regional Inequality

As stated above, the responsibility for providing personal assistance services rests with local governments whose expenditures for the service are subsidized by the central state. Since the services provided in a given community will depend on awareness of needs, political priorities and municipal finances, extent and quality of personal assistance vary widely among municipalities. As a result, persons with disabilities depending on these services face severe restrictions in their geographical mobility unexperienced by their non-disabled peers. Within the County of Stockholm, for example, an area consisting of some 24 separate municipalities, individuals with needs of personal assistance during the night and on weekends who cannot arrange these services through their families or by hiring assistants with their own money, are able to live in only half a dozen communities without running the risk of having to move to a county institution.

In this regard then the decentralization of social services to the local level, as prescribed by Swedish legislation, has been detrimental to the efforts made by people with disabilities in becoming equal participants in society. In the view of this writer financial responsibility for personal assistance has to be as centralized as possible, that is, be paid for *in toto* by national income tax revenues in order to avoid regional inequities. A possible vehicle for such a transfer at present would be an expanded National Disability Allowance (handikappersättning). The program which was described above is meant to compensate persons with disabilities for the additional cost of living incurred as a consequence of their disability.

At the same time, this solution would allow the control over the service to be as de-centralized as possible; consumers, if they so wished, could administer the funds necessary for hiring their own assistants themselves or turn over the money to the city's social service office or some private agency that could provide the service. The choice would always be the consumer's.

Funding personal assistance at the central state level through the present disability allowance would also keep more persons with disabilities out of costly institutions. As was pointed out in previous sections, the present division of financial responsibility for personal assistance and health care between municipality and county gives financial rewards to those municipalities which provide a minimum of personal assistance services; persons who cannot manage on such a minimum will have to be referred to nursing homes which the county pays for. With central state funding for personal assistance shuffling people with disabilities around would come to an end, since consumers would have the means to purchase the services anywhere.

Limited Choices

In Sweden the alternatives for persons with extensive disabilities in housing and personal assistance are still severely limited. The options for people needing extensive personal assistance are living with their families, in nursing homes, using the municipal personal assistance service while living in the community, and cluster housing.

In communities with poorly developed personal assistance programs, as developed above, people with disabilities are often forced to get services from their relatives after office hours and on weekends. When parents or spouses are no longer capable of providing the necessary practical aid, there is often no other place to go but the nursing home—especially, if the person has never had the opportunity of acquiring the skills of living on his or her own. Nursing homes, the Swedish disability organizations contend, should never be considered an acceptable housing solution for people who do not have to live there on medical grounds. Despite public statements by Swedish politicians on their committment to de-institutionalization and on its economic advantages there are still people with disabilities living in nursing homes, often people in their early twenties, purely for lack of appropriate personal assistance services in their communities.

Given these choices, or rather lack of them, the advent and development of cluster housing has been embraced by public officials and consumer organizations alike as the solution to the housing problems of persons requiring extensive personal assistance. The number of persons aged 20-65 in need of this arrangement has been estimated at some 10,000 which, for comparison, is 0.12 per cent of the total Swedish population or more than two thirds of all Swedish wheelchair users in that age bracket. The estimate made by one of the most powerful Swedish disability organizations has gone unchallenged.[43] While the estimate may be correct as far as the number of persons is concerned who are in need of more extensive personal assistance, the conclusion that these assistance needs have to be met in cluster housing arrangements **only** must be considered unfounded.

The cluster housing solution, some consumers point out, implies that people with disabilities have to move to where the services are and not the other way around. The result is a severe restriction of the geographical and social mobility of people with disabilities in need of personal assistance which profoundly limits their possibilities for full participation and equality. The term "koncentrat" (concentration) commonly used in the jargon of the Stockholm Office of Social Services for cluster housing is a good description of the geographical limitation and the semi-institutional character of this solution. Cluster housing is presently not available in all communities and in

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[43] As quoted in Månsson, K.C., *Housing with Day and Night Services for the Severely Disabled*, The Swedish Institute for the Handicapped, Stockholm, 1982

all neighborhoods. Nor does it allow tenants to live in any other form of housing than apartments in multi-family structures.[14] Also, unlike in regular lease contracts tenants of *boendeservice* units are not free to swap apartments with anybody they choose. In Stockholm's tight housing market exchanging apartments is an easy and popular method of adjusting one's housing to changing needs. For tenants of *boendeservice* apartments, however, exchanges are possible only with persons who qualify for *boendeservice* according to the Social Service Office's criteria.

STIL: Consumer Reaction in the Form of An Incipient Independent Living Movement

As a result of a seminar[15] on the Independent Living Movement in Stockholm in December 1983 Stockholm's Independent Living Group (STIL) was formed with the objective of increasing the number of personal assistance alternatives for persons with extensive disabilities. While STIL does not deny the advantages of *boendeservice* over institutions or parental homes, its members argue that *boendeservice* as the only solution cannot satisfy different, individual needs. Persons with extensive disabilities, according to STIL, despite their common need of personal assistance are individuals with different personalities and social and economic background who have the same right to find their own way of living as their non-disabled peers. The flexibility implied by this right, STIL members claim, depends on two requirements:

- not linking housing and services into one bundle as in cluster housing
- municipal or, preferably, central state personal assistance allowances directly paid to the consumers to enable them to purchase the services from whomever they choose.

Personal assistance programs that incorporate these two principles, STIL members contend, enable individual consumers to custom-design their own assistance system by making all decisions as to staffing, scheduling, training, hiring, and firing. In order to demonstrate the feasibility of such solutions STIL is preparing a pilot project where consumers of personal assistance will function as employers of their assistants. STIL is currently negotiating with the City of Stockholm for an agreement where the participants in STIL's project will receive the amount that the city presently spends on the respective individual's personal assistance. The funds will then be

[14] Recently a few cities, such as Gothenburg, have started *boendeservice* units where consumers live in single-family row houses. Because of the lower density of single-family housing this solution involves larger walking distances for the staff and has not been popular with the unions.

[15] Participants from the United States were Judith Heumann and Edward Roberts, World Institute on Disability, Berkeley, California. From the United Kingdom came Ken Davies, Derbyshire Coalition of Disabled Citizens and Neill Slatter, Hampshire Independent Living Center.

administered by the participants either individually or in form of a cooperative. Participants will have the choice of taking on the administrative tasks associated with being an employer or charging the cooperative with that task.

Since STIL's membership consists of individuals with extensive disabilities facing very limited housing choices, the organization's initiative is seen mainly as a protest against cluster housing. While *boendeservice* has its rightful place among the present limited housing and personal assistance alternatives in Sweden, these recent developments indicate that consumers there have begun to question the monopoly position this solution has had for so long.

The hypothesis is here suggested that when the number of cluster housing apartments in a given community increases beyond a certain level relative to the number of persons in need of personal asistance, the only other alternative for many, a nursing home, ceases to serve as the sole reference point and other imaginable solutions are explored that promise more degrees of freedom. Perhaps it is no coincidence that STIL was founded in Stockholm which is the city with most cluster housing apartments per capita in Sweden, presently 150 apartments in a total population of some 600,000 inhabitants. The most active members in STIL are residents of *boendeservice* units who expect considerable improvements in their whole life situation from moving out and administering their own assistance service.

As an aside, the above argument might explain why the Fokus scheme seems to face less criticisms in the Netherlands than *boendeservice* in Sweden—despite the fact that the Dutch cluster housing solution has retained more of the institutional characteristics[66] of the original Swedish Fokus scheme than *boendeservice*. People with extensive needs of personal assistance have apparently considerably fewer alternatives in the Netherlands than in Sweden which can be shown by some rough calculations.

The number of persons in the age bracket 18 to 65 and in need of extensive personal assistance has been estimated at roughly 10,000 in Sweden and 15,000 in the Netherlands.[67] In the Netherlands, as of 1984, approximately 1,300 persons or 9 per cent were housed in residential centers

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[66] Dutch Fokus units, for example, consist of 10-15 apartments whereas *boendeservice* units have 5-10 apartments. Dutch Fokus units, in contrast to Swedish *boendeservice*, are still built with common kitchen, dining, laundry, and bathing facilities. Judging from the account of Gerben DeJong (*Independent Living & Disability Policy in the Netherlands: Three Models of Residential Care & Independent Living*, World Rehabilitaton Fund, Report #27, New York, 1984) assistance with household chores in Dutch Fokus units is not available before 8 a.m. and after 6 p.m. which makes for late breakfasts and early dinners, nor seems to exist the possibility of using Fokus assistants outside one's home. In Swedish *boendeservice* units assistants are supposed to be available for household chores and outings as long as there is enough staff for the other tenants' needs.

[67] Ratzka, A., "Speculations on the Future of the Fokus Scheme" in DeJong, G., *op. cit.*, p. 87.

such as Het Dorp[18] (an entire village of 400 inhabitants in need of personal assistance); 200 or a little more than 1 per cent lived in Fokus units; and the remainder, about 13,500 or 90 per cent, stayed either in nursing homes or had to rely entirely on family for assistance, since there is no personal assistance program for persons living outside residential centers or Fokus.[19] In Sweden residential centers such as Het Dorp and its smaller versions are unknown and would be unacceptable to disability organizations and policy makers. About 1,000 persons or 10 per cent live in cluster housing; some 3,000 or 30 per cent live in nursing homes;[20] the remaining 6,000 or 60 per cent live at home with personal assistance provided by municipal home helpers. Since in many communities such assistance is not available after office hours, an unknown percentage in this group has to rely on supplemental assistance from family members or other sources.

Fokus housing in the Netherlands offers comparative advantages which help to explain its popularity. In a very tight housing market and without national accessibility codes in residential construction it is apparently very difficult to secure accessible housing in the Netherlands which makes the relatively spacious and subsidized Fokus apartments very attractive. Also, Fokus housing with ADL-assistance paid for by state insurance is financially considerably more attractive than the residential center alternative where the resident is left with a mere pocket money or living at home in the regular housing stock where assistance has to be provided by family members or has to be purchased with the consumer's own money.[21] In Sweden *boendeservice* offers no such financial incentives.

Under such circumstances there is no way of knowing how much of the Fokus scheme's popularity in the Netherlands is explained by its intrinsic qualities and how much is merely due to the overwhelming lack of better alternatives tolerated by a weak consumer movement.

STIL's initiative has met considerable interest and also initial resistance—the latter not surprisingly from the established disability organizations who are strongly committed to the *boendeservice* model. In STIL's view one of the reasons, why cluster housing has become the main solution propagated by these organizations, is the fact that Swedish disability advocates traditionally have often been persons who do not need personal assistance or have no disability themselves and who therefore lack a first-hand understanding of

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[18] For a personal account on Het Dorp see Zola, I.K., *Missing Pieces: A Chronicle of Living with a Disability*, Temple University Press, Philadelphia, 1982.

[19] DeJong, G., *op. cit.*, p. 53.

[20] In 1981 an estimated 7,000 persons of all ages were staying in nursing homes who could manage to live in their homes with several hours of personal assistance a day. ("Boendeservice i varje kommun", *Svensk handikapptidskrift*, Vol 58, No 9-10, Oct. 1981, p. 21) Today, this figure is probably lower. Also, since most of the people in this group were 65 or older, the number of persons in the age group 18-65 most likely does not exceed 3,000.

[21] DeJong, G., *op. cit.*, p.64.

the importance of personal assistance for a self-directed life. STIL has recognized this limitation and does not permit persons without need of personal assistance on its board.

Interestingly, much of the initial resistance has come from the political left who opposed STIL's proposed models of consumer control as "individualistic". The argument is that personal assistance is the responsibility of and should be administered by public bodies under full control of the democratic process instead of private and perhaps even profit-oriented interests. In this position STIL's initiative is seen as part of the recent "privatization" wave which proposes private and often profit-making solutions for services, such as health care, which in Sweden have traditionally been considered to be in the public domain. STIL members respond that they do not see themselves as helpless hospitalized patients who need protection from private profiteers but as healthy, self-directed individuals living in their own home and pursuing an active life who know what is in their best interest. STIL also points out that it must be in the interest of all forms of government that some decisions remain in the private sphere and are not subject to public control, namely, decisions about such mundane everyday tasks as when and how to go to the toilet. The attitude of critics on the left towards STIL has improved considerably after it was announced that participants in the pilot project, if they so wish, will form a consumer cooperative which functions as the employer of their assistants.

Swedish unions are known for their reluctance to support de-institutionalization fearing that they cannot protect their members' interests outside of large institutions. Thus, they have been critical of STIL's proposals arguing that personal assistants could easily be exploited, if employed by individual consumers. Today, due to pressure from the unions municipal Social Service Offices have issued a multitude of rules that regulate in detail the tasks assistants are to work with. STIL contends that in the consumer-assistant relationship, made possible in the STIL-project, both have equal opportunities for and an interest in establishing a satisfactory working climate where both parts together can reach agreements. In this way, assistants too can choose whom they want to work for in contrast to the regular municipal home help service or *boendeservice* where they can be ordered to go to anybody. More than 10 per cent of STIL's membership consists of *boendeservice* workers who support STIL's initiative in the hope of improving their own working conditions through the pilot project.

One of the most persistent arguments against STIL's personal assistance initiative is the contention that not many persons with disabilities have the ability to manage their own personal assistance. These doubts are most often advanced by social services professionals and by non-disabled functionaries of disability organizations some of whom have called the proposed STIL project "elitist". STIL's reply is that even if not all consumers are willing or

able to administer their own personal assistance service, this, in itself, would not constitute sufficient grounds for hindering those who are able and willing from doing so. In most other areas differences in needs and aptitudes among citizens are recognized. In fact, insisting that all consumers of personal assistance should have the same system, STIL contents, is reminiscent of the stereotyping attitudes which people with disabilities have been exposed to for so long. By assuming that all consumers of personal assistance have the same needs, abilities, and preferences this type of prejudice in effect denies people with disabilities their uniqueness as persons.

In order to give as many consumers as possible the opportunity of administering their own personal assistance STIL has on its program peer support groups and peer counselling courses where consumers can acquire the necessary administrative skills and train to become more self-directed and assertive individuals.

When pointing to the documented success of consumer-controlled personal assistance services as they exist, for example, in California, England, New York City, and Denmark,[2] the reply is often that in Sweden there is a different social climate where local governments are strongly committed to providing such services. Swedish law in this area (socialtjänstlagen) counts people with disabilities among the "weak" groups in society together with children, older people, immigrants, etc. whose special protection local governments are charged with. As it is often put, "in Sweden we take care of each other". In this climate consumer-run assistance services are seen as a necessity in the US to which people with disabilities in Sweden do not have to be exposed to. The fact that in Denmark (whose social welfare policies are quite similar to Sweden's) individuals with extensive disabilities have had personal assistance schemes,[3] as propagated by STIL, since the late 1950's is quite disconcerting to advocates of this position.

The language used by STIL seems to stir up sentiments, such as STIL's insistence on individual control over hiring and firing. In a social climate where terms like "home samaritan" were developed, the thought that persons who have extensive disabilities and depend on physical help should be able to **fire** their "samaritans" is a provocation to many. The same is true for STIL's demand that individual consumers have to be able to be employers of their workers, if they so choose. While anyone is legally free to hire other persons' services, to some people in Sweden, the word "employer" seems to

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[2] Rosenfeld, D., *Cost Comparison of 37 Ventilator Dependent Individuals: Hospitalization vs. Home Care*, Concepts of Independence, Inc., New York, 1985. For information on California and England (St. Thomas Hospital, London) see Laurie, G., *op. cit.* For information on Denmark see Ann Isberg's paper presented at the Third International Polio and Independent Living Conference, St. Louis, Missouri, May 1985 sponsored by the Gazette International Networking Institute, St. Louis, Missouri.

[3] The pertinent legislation in Denmark is § 48,3 of the Danish Social Services Act (bistandsloven)

carry the connotation of upper class membership. The thought of people with disabilities as employers might cause some discomfort then, because it would turn their perception of the social order upside down where people with disabilities have always been at the bottom of the totem pole.

STIL which considers itself as part of the world-wide Independent Living Movement points to the uneven distribution of power in the encounter between professional service provider and consumer and talks about the need for people with disabilities to empower themselves. Many persons including individuals with disabilities dislike the word "power" in this context. Persons with disabilities are apparently not expected to be self-directed and assertive, since physical dependence is often automatically associated with emotional dependence.

IV. RESEARCH ISSUES

Despite the fact that public personal assistance programs have been in existence in Sweden for over 50 years there has been surprisingly little in the way of policy evaluation. The work that has been done in this area is restricted to gathering descriptive statistics on numbers of hours provided by type of service, number of consumers, staff, and expenditures.[74] Decisions on the extent and organizational form of the services seem to be made by local politicians and administrators without virtually any analytic research on questions such as needs assessment, quality of services, impact of the service on consumers' lives, the rate of substitution between personal assistance and other services for people with disabilities, or the influence of personal assistance on the incidence of institutionalization.

Sweden is probably one of the countries with the oldest and most extensive experience in this area. For these reasons and because of the country's longstanding tradition of keeping excellent records Sweden provides a unique opportunity for in-depth studies of personal assistance. Research on Swedish personal assistance delivery systems, with due consideration of the problems of transferring programs from one social policy climate and institutional framework to another, can provide valuable policy information to disability advocates, social policy decision makers, and service providers in other countries where the establishment or expansion of existing services is contemplated.

In the following a very brief discussion of some of the research issues raised by Swedish personal assistance schemes is provided.

Needs Assessment

When reading the scanty literature on personal assistance services in various countries it is interesting to note the difference in estimates of what part of the population needs such services. Looking at West German and Swedish statistics, for example, the incidence of a functional disability requiring community-based personal assistance in West Germany is estimated at 2.9 per cent of the total population eight years and older[75] whereas in Sweden this figure has been found to be 8.1 per cent solely in the age group 15 to 75.[76]

A question for research then, would be to analyze the cross-country differences in needs assessments. First, a model of the determinants of aggregate needs would have to be constructed which could include such demographic variables as age mix, incidence of certain diseases and accidents, family

[74] National Central Bureau of Statistics, *op. cit.*; Daatland, S.O. and Sundström, G., op.cit.

[75] Bundesministerium für Jugend, Familie und Gesundheit, *Anzahl und Situation zuhause lebender Pflegebedürftiger*, Stuttgart, 1980.

[76] Blomgren, L. and Brattgard, S.O., *The Risk of Becoming A Wheelchair User—A Method to Calculate the Risk of Becoming Disabled*, Handikappforskningen, Gothenburg University, 1979.

structure, urban-rural mix, and women's participation in the labor force. Other determinants which come to mind would be a series of policy variables such as provision of technical aids, availability of rehabilitation services, accessibility of the housing stock, housing adaptation programs, rates of institutionalization as well as financing mechanisms of personal assistance and residential institutions. Finally, an explanation of the observed cross-country differences in needs assessments would have to look into cultural differences, in particular, the attitudes towards people with disabilities, the underlying assumptions as to their ability to participate, and to what degree these attitudes have been internalized by persons with disabilities.

Re-defining Institutions

The dissatisfaction with the limited number of housing alternatives for persons requiring extensive personal assistance that has led to the formation of STIL is primarily directed against cluster housing or *boendeservice* as **the** housing solution for people with extensive disabilities. The proponents of cluster housing claim that *boendeservice* is an alternative to institutional living: tenants live in their own apartments which outwardly are indistinguishable from neighboring units, a maximum number of ten *boendeservice* apartments is dispersed throughout a large apartment complex guaranteeing geographical integration, and residents are free to come and go.

On the other hand, *boendeservice* tenants point out a series of problems that they experience in connection with the staff: Workers sometimes do not respect tenants' privacy and enter the apartment with the staff key without ringing at the door; staff is suspected of spreading intimate details of the residents' lives; workers discuss and determine which activities of the residents they are to support. Other common complaints have already been mentioned such as tenants' lack of input in staffing decisions, rules about the type of bed, etc. a resident is allowed to have or the geographical limitations *boendeservice* entails. The list could be continued. Many of these grievances are reminiscent of the critique directed against institutions such as hospitals. It would seem then that there is some evidence that institutions do not necessarily have to consist of brick and mortar but can also be of the "ambulatory" type.

An area where more work has to be done then is the question of what constitutes an institution. One approach might be to compile a list of features which are commonly associated with institutions and to examine which of these properties also apply to cluster housing and similar solutions.

One feature suggested here as a central characteristic of institutions is that the consumer in facing the staff does not meet individuals on a one-to-one basis but is dealing with a hierarchically ordered organization that has its written and unwritten rules, formal and informal goals, and a tradition of its own. It is in the nature of a hierarchically organized chain of command that, as an order or rule is passed down from one echelon to the next, its interpretation automatically

becomes narrower as employees will limit their own margins for decision making in order to avoid the risk of making a mistake. Since the cluster housing concept depends on a staff, there are definite limits to the extent to which *boendeservice* can be improved—a conclusion which is not shared by the established disability organizations in Sweden. Another property that institutions seem to have in common are the limited choices, in particular, the lack of opportunities for consumers to formulate their own alternatives.

Given the popularity of cluster housing among planners in Sweden and abroad and considering the known effects of institutions in the form of hospitalism, lack of self-confidence, and stunted personal growth it is of paramount importance that we properly label housing and assistance solutions. Institutional vestiges in service delivery have to be identified before programs can be designed which truly support the emancipation of people with disabilities.

Degree of Consumer Control and Independent Living Outcomes

Service delivery systems for people with disabilities and older people can be designed with varying degrees of consumer involvement. The Independent Living Movement demands that consumers both as a group and as individuals have to be in control over the services which they need for a self-directed and productive life. An interesting topic for research would be then to test this contention and to analyze the differential effects, if any, that personal assistance services with differing degrees of consumer control have on consumers' lives. A hypothesis might be that the larger the extent of consumer involvement, the greater would be consumer satisfaction and productivity. The operational definitions for these outcomes could include such health related items as incidence of infections and pressure sores as well as other variables such as number of hours a week spent on gainful employment, volunteer work, sports, and other active leisure time activities.

There are several considerations which seem to support this hypothesis. On a practical level, the personal assistance programs presently available do not allow a great degree of flexibility. A system that permits more input from the individual consumer will most likely be more responsive to his or her needs and will enable the user to be more active. Further, taking over a larger share in administration, staffing decisions and other responsibilites of one's personal assistance service must be considered a valuable training. The skills and confidence acquired this way can be usefully applied to other areas such as employment. Finally, the frustration and dissatisfaction reported by many persons with extensive disabilities in Sweden might, in part, be the result of the experience of dependence on other people, in particular, social workers whose task it is to organize the various services for their clients. As one STIL member put it, "my life is run by other people". Control over a service which is central to one's daily life and the opportunity of bringing about changes

through one's own efforts with the risk of failure and the rewards for succeeding are bound to decrease alienation and might well lead to a better self-esteem which can carry over to other spheres of one's life.

Quality Criteria

Consumer input in research on personal assistance and on social policy in the disability area in general has been minimal in Sweden. It would seem that efforts in this field have been mainly initiated by public agencies or professionals with little affiliation with people with disabilities. As a result, the research questions asked have reflected more the needs of service providers than those of consumers. A case in point is the issue of the quality of personal assistance delivery systems. While there is concern about the relative costs of some schemes as compared to other schemes, the quality of the service as a consideration typically does not enter the comparisons—a criterion that is uppermost in the consumer's mind.

In Sweden and other countries the tightening economy is often used as an argument for cutting public expenditures for social welfare programs. In such a climate disability advocates, instead of pushing for more services which would bring people with disabilities closer to the goal of full participation and equality, find themselves more often on the defensive. In meeting the present preoccupation with cost containment among policymakers, service providers, and the public at large, people with disabilities have to point out that budget cuts most often simply lead to quality deterioration in service delivery: half a loaf of bread is cheaper than a whole loaf. Unfortunately, quality is not as easily measured as cost. In order to document how changes in funding affect the quality of personal assistance programs a measure of quality, as described below, would be an important tool.

The need for a measure of quality is also brought out by the following consideration. One of the strongest arguments for de-institutionalization the world over is the contention that it is cheaper for the tax-payer, if people with disabilities and older persons live integrated in the community. There are countless relative cost studies that have proven this point over and over. On the other hand, these investigations hardly ever consider the difference in the quality of life afforded by institutional and independent living settings. Assume an institution with the standard of a Third World prison or an asylum of 100 years ago. To keep somebody in such a hypothetical institution would certainly be cheaper than to provide the supportive services necessary for an independent and dignified life in the community. Thus, if the level of quality of life is not made an explicit issue, reliance on the cost savings argument can backfire.

Consumer-oriented quality criteria to be used in the comparison and evaluation of different personal assistance systems would have to include items such as:

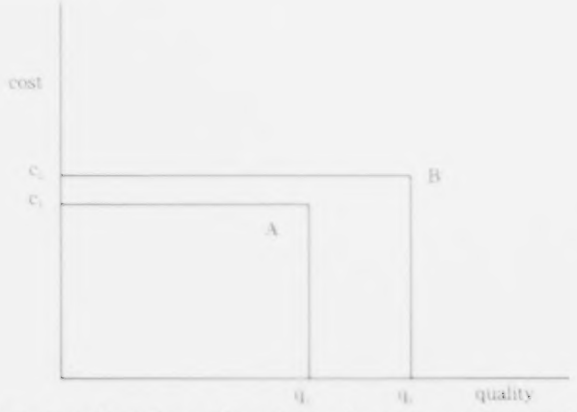
- turnover rates among workers;

- reliability and punctuality of assistants;
- range of tasks which may be carried out by assistants;
- intensity of service, i.e. maximum amount of hours granted and at what times;
- geographical mobility permitted by the service (at home, work site, outside the community, abroad);
- consumer's control over who will carry out the work;
- flexibility and consumer control in scheduling assistants;
- time spent by consumer in the administration of the service;
- degree of consumer input, i.e. the possibility to take on functions such as advertizing, interviewing, hiring, paying, training, and firing.

Conceptually, an index consisting of these characteristics can be used to compare different personal assistance services in respect to both cost and quality.[5]

In such a quality index the items enumerated above could serve as some of the dimensions that define the concept of quality in personal assistance services. One of the methodological difficulties in the operationalization of such an index would be to find the appropriate weights which people with disabilities have to be attached to the various dimensions that the index consists of. The weights will differ depending upon the individual consumer's needs which, in turn, are a function of, among other things, extent of disability and the tasks one requires assistance with. Single parents with

[5] The comparison would consist of mapping different personal assistance services onto a two-dimensional space where each service is represented by the matched pair of the cost and quality measures. Comparing two different services, service A and service B, would then look as follows.



Planners trying to change Service B into Service A in an attempt to save tax funds have to be confronted with the resulting decrease in quality. The decision here is whether the savings are worth the loss in quality.

disabilities and small children, for example, might place more emphasis on such criteria as low workers' turnover, reliability, and punctuality than, say, the geographical mobility permitted by the service. One of the spin-offs of the construction of such an index would be information on what hierarchy of demands different groups of people with disabilities place on their personal assistance service.

The most important guideline in constructing a quality measure should be derived from a comparison of citizens with disabilities and their non-disabled peers. If the aim is to be full emancipation and participation, people with disabilities have to have the same degrees of freedom in all important aspects of life be it education, employment, transportation, housing, political, economic, social, and cultural life of their community. Work in this area would not only encourage consumers to formulate their needs but would also, most likely, point out the necessity of service delivery systems which are so flexible that they can accomodate diverging consumer requirements.

Designing Programs for a Continuum of Consumer Control and Consumer Needs

Personal assistance programs in Sweden, as has been pointed out above, are charaterized by a high degree of professionalization and a concomitant low level of consumer input. If consumers are to enjoy the benefits of more control over this vital service, new forms of service delivery have to be designed. The most important feature of such future systems has to be flexibility. While it is recognized that not all consumers will be willing or capable of taking on maximum responsibility in the administration of their own personal assistance system, each consumer has to be able to exercise precisely that level of personal responsibility over the service and perform those adminstrative tasks that he or she feels comfortable with at a given point in time. Moving from one level of responsibility to another has to be possible in either direction—both up and down, with a minimum of bureaucratic effort.

The tasks involved in the administration of personal assistance systems include negotiating with the sponsoring government agency for the necessary funds, recruitment of workers (advertizing, interviewing, screening, formulating a contract, hiring, and firing), as well as training, motivating, supervising, and scheduling the assistants. Consumers have to be able to formulate their needs as to the number of hours and type of assistance, the time of the day and week the work is to be performed, what skills are required from the workers and how the work is to be done. Other tasks involve setting up routines for payment of wages, bookkeeping, and accounting to the funding agency. The legal responsibilites of employers

include tax withholding, payment of employer's fees, fringe benefits, and, in general, the observation of the legal aspects which regulate the employer-employee relationship.

In designing flexible systems the task is then to divide the above list of responsibilities among individual consumer, consumer groups or cooperatives, private consulting firms, and funding government agency in such ways that a multitude of different levels of consumer control is guaranteed.

According to one of the tenets of the Independent Living Movement, all people—including the mentally retarded—can increase their capacity for self-direction, if the right circumstances are given. Thus, systems for the support, training, and protection of consumers have to be developed which aid users at each point. Effective methods based on the concept of peer counselling have been developed at Centers for Independent Living in the United States.[79] There, consumers can take Independent Living Skills classes under the guidance of teachers who share the fruits of their own personal experience with disability and serve as role models.

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[79] See for example, Saxton, N., "Peer Counseling," in Crewe, N.M., Zola, I. K. *et al.*, *op. cit.*

V. IN CLOSING

The present organization of Swedish personal assistance services dates back to the 1930's. To have a social program that is that old can be a mixed blessing. On the one hand, services that have been around for so long will, for the most part, enjoy broad political support. On the other hand, vested interests of policy makers and civil servants as well as the dynamics of a large administrative apparatus will tend to preserve the program's organizational structure regardless of its appropriateness to changed circumstances. In addition, programs are seldom designed from the very start in such a way that they will remain flexible and open for changes in the years to come. Thus, a service that once was considered very progressive can become outmoded with time as society develops and the needs of consumers change. This crustification can continue relatively undisturbed, if there are poorly developed built-in mechanisms for feedback and correction. In the case of Swedish personal assistance services, a high degree of professionalization and resulting low consumer input coupled with lack of alternatives for consumers protected the programs from the necessity of re-evaluation and change. In the opinion of this writer, the situation has been exacerbated by the fact that Swedish disability advocates in the past have often been persons without need of personal assstance who lack a first-hand understanding of the importance of personal assistance for a self-directed life.

When persons with more extensive disabilities, e.g. high spinal cord lesions or the need of mechanical ventilation, could stay alive thanks to the medical and technological advances of the last decades, their needs of personal assistance were most often not met by existing programs. Instead of changing and expanding the services so that this group could live in the regular housing stock in the community, semi-institutional cluster housing was developed. Also, as these often younger consumers survived, the professional and hierarchically structured organization from the 1930's was not adjusted to allow an active and self-directed lifestyle.

Recent developments such as the founding of STIL point to long overdue changes in Swedish personal assistance programs. These changes will also affect service delivery to older people who form the majority of all personal assistance users. The improvements for people with disabilities over the last two decades, both in material and in attitudinal terms, will in the future make it easier for older people with disabilities to identify themselves as members of the disabled minority. Once this step has been made, they can be expected to raise their demands and to push for flexible, consumer-controlled programs.

The trend towards consumer participation in decision making is supported by the intentions of recent legislation (socialtjänstlagen). At the same time, we can observe an increasing professionalization within all

workers' categories. How these potentially conflicting developments will be resolved is still unclear: will consumer input be coopted by the professionals or can professionalization be utilized for the purposes of the consumers?

If the Swedish consumer movement succeeds in gaining control over personal assistance programs, Sweden could become an outstanding model for many other countries in this respect; the high level of funding that the country is already committed to coupled with consumer control would turn these services into true vehicles of emancipation.

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APPENDIX:

Design Criteria for Personal Assistance Programs

The extensive Swedish experience with personal assistance schemes can provide important information to consumer advocates, service providers, and policy makers in other countries where the establishment of new or the expansion of existing services is under consideration. In the following a brief summary is presented of the implications of the material in this monograph for the design of personal assistance programs.

Overriding Criterion

People with disabilities are struggling for equality and full participation in their communities. This goal, I suggest, can be defined in more operational terms as reaching the same degrees of freedom as enjoyed by one's non-disabled peers in the areas of education, employment, housing, transportation, in political, economic, social, and family life, freedom of expression, and opportunities for realizing one's potential. Thus, the overriding design and evaluation criterion for existing programs and proposed measures must be how much closer a particular solution brings people with disabilities towards this goal.

The definition emphasizes that programs have to be evaluated with reference to the particular time and place persons with disabilities live in and to the individual's non-disabled peers. Service providers and policy makers in facing demands from disability advocates will often point out that in other cities or countries people with disabilities are worse off or that things are much better now than they were 20 years ago. These comparisons are irrelevant for people who want to live here and now.

Language and Attitudes

Language reveals and influences attitudes. Terms such as "attendant" and "care" should be avoided, since they carry institutional connotations and project the image of passivity and dependence. "Personal assistance" is suggested here, because this expression is believed to contribute to an image of consumers as self-directed, independent people who are capable of managing their own lives.

Consumers As Experts

Consumers are experts and must be decisively involved in designing the programs. The way personal assistance is organized can either thwart consumers' potential for growth and self-direction or enable them to live as active and productive members of their community.

Social policy is most often not made by the people whose lives are affected by it. Even if consumer groups sometimes succeed in lobbying for a reform, they rarely have the possibility of or an interest in getting involved in the actual design of policy instruments. Because of an alleged lack of

administrative experience or formal qualifications it is common to leave this work to administrators, social workers, medical doctors, and lawyers. Not only is there a growing number of professionally trained people within the rank and files of consumers, the importance of their expertise as consumers is often undervalued—even by themselves. Since consumers have the most intimate experience of how personal assistance influences their lives, they have to formulate their needs and translate them into design criteria. If the design of personal assistance programs is left to service providers, systems are likely to result that conform to the needs of the agency and not necessarily to the needs of the consumer.

Services for All Needs

Services must encompass all needs. In order to live full and active lives people with extensive disabilities need personal assistance for a variety of activities, such as personal hygiene, dressing, household chores, driving, shopping, sign language interpreting, in a variety of situations, for example, at home, work, play, in school, on trips, and on vacation. To break up these needs into several distinct programs for certain activities and certain situations can entail several funding sources and separate service delivery systems each with its own eligibility requirements, administrative routines, and staff. As the number of different agencies involved increases, so does the time and energy spent by the consumer and his or her vulnerability, since problems can arise in any link of the chain. The most far-reaching consequence is the sense of alienation and powerlessness which the division of responsibility for the programs breeds in consumers.

Choice and Changing Needs

General solutions cannot satisfy individual needs. Government agencies, if left alone, tend to develop a single solution that is to satisfy all needs, because from an administrative point of view a single service delivery system is preferred. Yet disabled people are unique individuals with individual physical and emotional needs, personal resources, and life circumstances. Also, for each individual needs will vary over time as family situation, occupational status, interests, and health change. Therefore, consumers need to have alternatives. Choice is the key to independent living. The best guarantee for responsive systems is consumer control.

Programs for Consumers' Productivity

In many countries personal assistance programs are means-tested which leads to undesirable consequences. Means-tested eligibility can act as an effective deterrent for gainful employment. Coverage of the costs of assistance is often seen by the general population and consumers as a welfare payment—an attitude which has stigmatizing effects.

For persons with extensive disabilities personal assistance is a basic condition for a dignified life and active participation in the community. Tax-funded personal assistance services should therefore be demanded as a fundamental civil right.

No Volunteer Programs

Do not design programs that rely on volunteers. Consumers do not have the same possibilities of demanding competent, punctual, and courteous work from volunteers as from assistants who are paid competitive wages. Consumers are likely to have more personal power and view themselves as more independent persons when they function as employers instead of objects of charity. The virtues of volunteerism and charity are most often espoused by conservative politicians whose motives are to cut taxes for the benefit of their voters.

Funding As Centralized As Possible

Funding has to be as centralized as possible—at the federal level. Single source funding at the federal level eliminates regional inequalities which otherwise seriously impede disabled people's geographical and social mobility. Only at the national income tax level all benefits from a personal assistance policy can be internalized; where personal assistance is financed by local governments and institutional care facilities by regional governments, local governments do not reap the financial benefits of de-institutionalization made possible by personal assistance. Personal assistance programs enable many citizens with disabilities to become gainfully employed thereby contributing to national income tax revenues. This is also true for family members who otherwise are often forced to informally provide these services and whom such programs enable to pursue employment outside the home.

Service Delivery As Decentralized As Possible

Control over service delivery has to be as de-centralized as possible—at the consumer level. Consumers are the best experts on their needs and must be able to decide what activities they need assistance with and how many different persons are to work. They have to have the right to recruit, hire, schedule, pay, and—if necessary—fire their staff. To rely on workers from an agency can involve high turnover which is inefficient. Individuals with extensive disabilities have specialized needs that differ from person to person. New workers have to be instructed and trained by the consumer which takes time and effort. Having to depend on strangers can be humiliating, since the work constitutes a close social relationship and consists of very personal and intimate activities. The assumption that any assistant can work for any person amounts to a denial of an individual's uniqueness as human being.

Consumers have to be able to choose that level of control over the various aspects of service delivery which they feel comfortable with. Towards this end they have to be offered support and training, ideally, by organizations of disabled people.

Among the benefits of assuming responsibility for one's personal assistance system are the acquisition of useful management skills, the dignity of being able to make mistakes, and the rewards of learning from them. These experiences and social skills are useful for other areas of one's life, such as employment, and lead to increased self-confidence.

Worker Professionalization vs. Consumer Expertise

Avoid worker professionalization—build up consumer expertise. Administrators and trade unions often propagate more professionalism in the hope of upgrading assistants' status and improving the service. The criteria for professionalism, commonly health care-related qualifications and training, represent obstacles to consumers' realization of their potential for self-direction, if the attitude is conveyed that consumers are passive patients who need to be taken care of. Consumers who want to improve the quality of the service and thereby the quality of their lives have to take more initiative and work with their assistants as a team where consumers instruct and direct. In order to support consumers in this role Independent Living Skills and Peer Counselling Classes have to be offered by organizations of disabled people.

"Ambulatory" Institutions

Watch out for "ambulatory" institutions. Institutions do not have to consist of brick and mortar. If consumers cannot choose who is to work for them, if they have to accept services without alternatives and do not meet assistants as individuals on a one-to-one basis but instead are dealing with a hierarchically ordered organization with its written and unwritten rules, formal and informal goals, and a tradition of its own, then they are facing an institution.

Typical for institutions is that, as orders or rules are passed down from one echelon to the next, their interpretation automatically becomes narrower as employees voluntarily limit their own margins for decision making in order to avoid making a mistake. The individual consumer being at the bottom of the pyramid becomes a powerless object in a machinery.

The effects of institutions are known, they cause loss of social skills and self-confidence as well as stunted personal growth. Therefore, institutional features in service delivery systems have to be identified and eliminated before programs can be designed which truly support disabled people's emancipation.

COMMENTARY
Carolyn L. Vash, Ph.D., Consultant
Planning Systems International

I recall that Gerben DeJong's monograph Planning Systems International (monograph 27 in the WRF Series) which described the Netherlands' cluster housing, stated that the Dutch had learned from Sweden's experience, thereby avoiding some of their mistakes. After reading this monograph by Ratzka, I certainly hope so! From DeJong's description, cluster housing sounded like a possible solution if/when my husband and I feel we'd be better off to abandon our private home for a senior citizens' collective of some sort. Having recently "case managed" the decline-to-death ordeal for three aged relatives—one right after another—I was keenly aware of how vulnerable we are to the possibilities of steadily decreasing physical and mental functioning as time marches on. The Dutch concept suggested you could get physical help but continue to call the life-decision shots yourself. Swedish cluster housing sounds like you pay for the physical help you get by turning over to the municipality the control of your life—even if you're fully capable of doing all the social management decision making that needs to be done. The devil offered Faust a better deal.

Ratzka has alerted me to many dangers, but I think the cluster-housing-plus-services concept offers possibilities for the Vashes in their declining years and for others like us. For example, Leisure World is a posh California retirement community with some appeal. If it added a centralized cadre of shareable ADL assistants, it might attract folks like me who need only an hour or two of help per day plus help with an occasional trip to the toilet at night. It would be important to make sure the ADL assistants are *trained* to see themselves strictly as extensions of the service users' arms and legs, not their brains—UNLESS they are contracted for by a third party who has legal guardian or conservator status. In other words, there would be no room for the workers to use their own judgement that a service user is too "senile," "retarded," or "disturbed" to make ADL-assistance-related decisions. If a person has not been assigned a legal guardian or conservator, she/he makes his/her own decisions.

The training issue is very salient for me right now because I am involved in a Small Business Innovation Research (SBIR) grant-supported study to determine the feasibility of developing multi-media training packages relating to ADL assistance. We are in the information gathering stage and the information we are getting is that consumers are adamant about avoiding the "professionalization" Ratzka describes—to the point that most would rather forego admittedly nice-to-have pretrained skills than take a chance on getting the attitudinal mistraining they say they find with graduates of most training programs.

The strains of the song "It's the same the whole world over" kept ringing in my ears as I read Ratzka's discussions of the "attitude problem." People who help other people—whether as expert health professionals, as semi-skilled functionaries, or in other contexts and ways—seem rather consistently to fall into the same trap. They tend to *overgeneralize* the edge of competency they hold over the help recipients. "This person can't survive without my help" migrates from "in performing (certain) physical tasks" to encompass more—making judgements and decisions and so forth. How much more and how fast it happens are the main ways we consumers distinguish between folks with "good" attitudes and folks with "bad" attitudes because it happens at times and to some degree with almost everyone. For example, even my husband—who deeply-felt attitudes toward people with disabilities (and women!) are among the most genuinely egalitarian I know—sometimes migrates from "I need to dress Carolyn" to "I need to tell her which dress to wear on a hot day like this."

The crux of the matter may lie in the benign situation alluded to earlier—operating as an extension of a person's arms or legs without also acting as an extension of his/her brain. It's simply *harder* to do the one and not the other! It's not the way we're used to functioning. When one operates in a totally different mode from that which is usual, new and unusual demands are made. In the case at hand, *un*learning ordinary ways of being/acting, and substituting a "mindless" approach (that would probably not be adaptive in any other realm of living and acting) demands special attention and effort, and maybe even talent and skill.

Frankly, many consumers I've gathered information from do not view the problem so non-judgementally. They complain bitterly about attendants' "God complexes" or denounce those who use being needed as an ego crutch or more blatantly abuse power. Most take a middle view, but often incorporating the idea that since the job is marginal it draws many workers who have marginal self respect, which is in turn associated with projecting one's inadequacies onto others. Thus, with a worker population vulnerable to falling into compensatory "I'm Okay, You're Not" attitudes, any inadvertent bolstering of this tendency in a training program will endanger the person's future acceptability to consumers. To enhance their acceptability, such tendencies should be nipped in the bud, not reinforced.

Personally, I don't much care what attitudes my attendant harbors as long as she performs competently. As the Rev. Terry Cole Whitaker puts it, "What you think of me is none of my business." That's easy to say when you're a long-experienced administrator who is fully comfortable wearing bosses' shoes *and* have a personality that thrives on acknowledging and resolving conflict. It could be made easier for other ADL assistance users, too, and that's the kind of training they're asking for—how to hire, train, supervise, and fire an ADL assistant. However, there are a couple of other

issues that make supervising an attendant with less-than-laudatory attitudes easier for me than for the majority of such consumers. And they both have to do with money.

I was earning a living and paying my attendants out of my own pocket before SSI/Medicaid came into being—in fact, before their precursor, ATD, came into being. Consequently, my attendants have always seen me as a fiscally competent person who could pay them living wages and have enough left to lead a nice lifestyle myself. This accomplishes a great deal *structurally*, without requiring me to perform any clever management/supervisorial techniques I could be trained to do. It sets me up to be responded to as a power, an authority, the unequivocal boss to someone who unequivocally is not. At this time in my life I choose to live in semi-retirement to do writing, illustrating, composing, and designing for which I may or may not one day be paid. An income reduction is associated with this decision. It creates no problem in paying an attendant, however, because years ago I had the foresight to buy a home with a guest cottage on the property. I now trade rent and utilities for fifteen hours per week ADL assistance. The fact that paying wages from current earnings would be beyond my means right now in no way undermines my image as a fiscally competent person. I "bought insurance" against future shortfalls twenty years ago, and I am now using and enjoying the protection I bought.

And insurance, in my opinion, is where it's at for all of us with disabilities which cause our basic living expenses to be high. In the absence of any purchaseable policy, let alone a form of "national health insurance" for all people, in this country, I had to forge a highly idiocyncratic "policy" of my own as soon as I got professionally and economically established. My approach was to acquire some housing stock to use as barter for ADL assistance services. It solves part of the problem part of the time.

Virtually no one can afford severe disability in its acute hundreds-of-dollars-per-day stage out of pocket. That is why we have the phenomenon of health insurance. Hardly anyone can comfortably manage the thousands-of-dollars-per-year stages that comprise the rest of one's life. This is why we often refer to severe disability as "catastrophic." My self-styled insurance policy covers me as long as I can get by with fifteen hours services per week. But what happens when I can't? How rich would I have to be to ensure that I'd never have to use up my savings, paying for around-the-clock ADL assistance, until I had spent down to my last fifteen hundred bucks so I could join the structurally-defined fiscally incompetent who received what they must have just to survive through welfare?

I'm a psychologist but I confess I don't understand why we, the American people, have created a socio-politico-economic system which nearly everywhere includes "socialized" (tax supported) police and fire protection for all but does *not* include "socialized" (tax supported) health

protection for all nearly anywhere! Do we value our material possessions more than our own bodies? Are the medical entrepreneurs either that afraid or that effective in opposing such? Are we so foolish as to see only the implementation problems associated with the *particular* approaches used by other countries and to lose sight of the issue itself and the plenitude of alternate strategies to try? The answers are probably yes to all three questions, and to many more which could be asked. The point in mentioning these is to draw attention to the roles of general human values and of special interests and the common good in shaping socio-politico-economic decisions.

A universal or "national" tax-supported health insurance program which allows "policy holders" (citizens/residents) to use the providers of their choice in the ordinary marketplace would seem a good alternative to try. Obviously, it should cover all life-long health-condition-related expenses which could prove economically catastrophic. This could mean that people unlucky enough to become disabled wouldn't necessarily have the double bad luck of becoming structuraly incompetent. The invasion-of-privacy horror stories Ratzka tells of Sweden, which we've all heard here, wouldn't have to happen anymore. The secondary disabling effects of alienation and powerlessness and their tertiary effects of mental-disorder-added-to-physical-disorder, underproductivity, unemployment, and other socially costly aftermaths, could be prevented too. In the long run we might save money, but that isn't the point.

It's simply time to realize that life-sparing but permanently disabling accidents of birth, illness, and traumatic event don't have the same meaning they once did, the people to whom they happen don't play the same roles in society, and different ways to responding to them are coming about. I don't say should come about; I see it happening. The drama is unfolding, and those of us who have written in this book are documenting certain parts of it. So many people are now surviving disablement and flourishing. And I do mean *flourishing*. The disability experience has made them strong as individuals and the independent living movement has made them stronger in the collective. Getting their demands met for a national health insurance program that will ensure or preserve fiscal competence and integrity in the face of health-related disaster seems only a matter of time.

COMMENTARY
Hale Zucas, Program Analyst
World Institute on Disability

Hundreds of thousands of Americans have disabilities—ranging from spinal cord injury to arthritis to blindness to mental retardation—to a degree which impedes or prevents them from carrying out one, some, or most of the activities of daily living on their own. These individuals need assistance from others in performing such activities as getting up, dressing, moving about, reading, cleaning house, and shopping, to name only a few. This assistance, which has come to be known as "attendant services," is essential if these individuals are to come close to reaching their full potential. The availability of attendant services is thus crucial to the concept of independent living, which is defined in the U.S. in the National Policy for Persons with Disabilities (1983) as control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities.

The World Institute on Disability is a public policy center examining major issues from a disability perspective. Its founders, Ed Roberts, Judy Heumann and Joan Leon, have been among the leaders of the Independent Living Movement since its earliest stages. Therefore it made sense that, upon the Institute's establishment, attendant services was chosen as one of its major areas of emphasis.

WID's ultimate objective is the establishment of a system which makes appropriate, affordable attendant services available to anyone in the country who needs them. This is admittedly an ambitious goal, one which may take a decade or more to achieve. As its first step, WID is undertaking a series of studies in order to ascertain the extent and effectiveness of existing programs across the Untied States and selected foreign nations.

The information collected in the course of these research efforts will be made available to organizations and individuals working to establish or improve attendant services programs at the state or local level. The information also will be used as a basis for developing a recommended design for a national program. In order to formulate these recommendations, qualitative as well as quantitative data will be needed.

As a major part of its research efforts, WID is compiling a comprehensive inventory of the 150 publicly funded attendant services programs which are currently in operation across the United States. This survey, which is supported by a four year grant from the Charles Stewart Mott Foundation, will include the following information on each program: size and nature of population served, eligibility criteria (financial and disability-related), method(s) of delivery, types and amount of services provided, funding level and sources. This inventory is scheduled to be published in summer 1986.

Secondly, WID is undertaking an in-depth examination of attendant services programs in five selected states. In this study, funded with a grant from the Easter Seal Research Foundation, interviews are being conducted with key state legislators, administrative agencies personnel, community disability organizations and a small sample of users. Information gathered in these interviews will be used to describe the history and operations of each program, identify strengths and weaknesses, and assess its effectiveness. This study will be completed in 1987.

The information produced in these studies will, of course, be of great value in building the case for a national attendant services program in the U.S. and in deciding and determining the form such a program should take. At the same time, however, well-developed attendant services programs have evolved in several other countries, and it behooves us to take a good look at these programs in order to see what lessons they hold for us here in the U.S.

Among the foremost candidates for such scrutiny are the Netherlands and Sweden, whose service systems for disabled people have long been considered the most advanced in the world. The Dutch system was the subject of a previous monograph written by Dr. Gerben DeJong for The World Rehabilitation Fund's Monograph Series.

In the present volume, Dr. Adolf Ratzka examines the provisions made in Sweden for meeting the needs of people with disabilities. First Dr. Ratzka gives a brief overview of the other components and provisions of the Swedish service system, some of which, (such as the liberal provision for government-funded housing modifications) are very impressive. The bulk of the study is devoted to a thoroughgoing discussion of the Swedish system of "in-home personal assistance", an assessment of that system from an independent living perspective, and identification of issues needing further research.

Dr. Ratzka is perhaps uniquely qualified to undertake such a study. His extensive academic background has equipped him to research his subject rigorously. He is a firm believer in the concept of independent living (he has, as a matter of fact, founded the Stockholm Independent Living Group) and in the importance of attendant services to that concept. Most important, however, he has been a user of attendant services for 25 years. As an insider, he knows more about the system and understands it better than even the most diligent and interested outside observer could.

As Dr. Ratzka points out, the Swedish system has a number of positive aspects. For instance, it serves about 4% of Sweden's population, a proportion 10 times that served by the most comprehensive such program in this country. The Swedish system also serves people of all income levels, whereas almost all programs in the U.S. only serve people poor enough to be eligible for Medicaid.

On the other hand, the Swedish system has some definite shortcomings. Among other things, the Swedish attendant program has from the beginning been oriented toward serving elderly people with relatively moderate disabilities (as is indicated by the fact that the average recipient gets just 172 hours of service per year, or 3.6 hours per week). Another drawback is that attendant services in Sweden are largely under the control of local municipalities rather than the central government. This means that there is wide variation from city to city in the scope of services. It is, in fact, a misnomer to speak of a single "Swedish program."

A general consensus in the U.S. has emerged among experts and advocates in the field that attendant services programs should serve everyone who needs those services with minimal regard to income, and should be adaptable enough to serve people with a wide variety of needs. There are a number of more subtle issues, however, that as yet have received very little attention. The most valuable aspect of Dr. Ratzka's paper is that he imparts a new and different perspective to some of these issues.

For example, high turnover and low quality of attendants are common problems faced by attendant service programs. Some have advocated that training and/or certification programs for attendants be instituted in order to alleviate these problems. Dr. Ratzka points out, however, that such steps (along with the increasing trend in Sweden toward full-time employment) lead to the professionalization of attendant work. This professionalization tends to infringe on the user autonomy which Dr. Ratzka quite rightly holds to be paramount. If attendants undergo a formal training program, they may think they know it all and be less responsive to a user's instructions or wishes. As Dr. Ratzka says, "The question, then, is how both quality of personal assistance and worker satisfaction can be improved without turning the work into a profession." This question will not be easy to answer.

In conclusion, this paper is the first detailed discussion and analysis of an attendant services program that has been undertaken from a user's perspective. As such, it is a most valuable contribution to the burgeoning discussion of attendant services in the U.S. and around the world.

COMMENTARY
Margaret A. Nosek, Ph.D.,
Texas Institute for Rehabilitation Research

The anger and indignation I felt after reading Adolph Ratzka's manuscript has not waned, indeed it has intensified to the point of outrage and has joined with strong feelings of gratitude to Adolph Ratzka for so articulately showing us our possible future. Dr. Ratzka's descriptions of the real life circumstances of Swedes with disabilities who use government provided attendant services called to mind the degradation, humiliation, and imprisonment that we in the disability rights movement have dedicated our lives to erradicate. That the service which we view as the linchpin of independence could become instead such an oppressor is an anomoly and a tragedy. Dr. Ratzka's astute reading of the social subconscious as the root of this problem is a warning we must heed as we move toward a national attendant services system in America.

I am even more firmly convinced after reading this monograph that consumer control is the single most important element in the attendant service system we are trying to create. We as users of the service must have as much power as we can responsibly maintain to choose the provider and determine how and when the services are provided. The situation where an unknown and different person could appear at each call and where all service needs must be met during traditional business hours is an atrocity. It accurately reflects the shallow understanding of disability that has prevailed among able bodied service providers. The degree to which disabled Swedes have internalized this understanding is evidenced by the fact that they tolerated this system for three decades before realizing its effects and protesting.

Conceiving of attendant services in terms so heavily laden with bureaucracy is foreign to me. In my own life, I perceive of personal assistance as a relationship more than a service. I now have what I consider to be an ideal system for having my attendant needs met. I have arrived at it after many hard years of experimentation and deliberation. I have discovered that I could never pay my attendants what they are worth—how could I measure in money my very link to existence? I have also discovered that there are many people in the world who need money but have other needs which rank higher, needs such as planning their future, gaining cultural experiences, receiving emotional support for their interests and studies, etc. When I search for an attendant, I carefully consider their life situation and aspirations and compare these to what I can offer personally and financially. Granted, a certain amount of money provided directly or indirectly for living expenses at least is usually required, and whoever controls this amount often controls the conditions of the service. Fortunately, I am able to meet this

requirement through earnings. However, I spend a great deal of time analysing what else my attendants need and how I can create positive monuments in their lives. In return, I have gotten reliable and high quality assistance when I need it, cheerfully provided, and with a willingness to be flexible when necessary.

If we accept that individuals' needs are best met by personal support systems they design for themselves, and that the most productive relationships result when the higher life needs of both the disabled individual and the attendant are met, then we must focus on developing funding mechanisms which enhance and do not destroy these elements. As we in America actively advocate for a national attendant services program, let us not make the same mistake as the Swedes of being convinced that the bureaucratic approach to this problem will yield a humanistic result.

The following fourteen points which should characterize a national attendant services system were drafted at a conference sponsored by the World Rehabilitation Fund and further refined at a symposium sponsored by the National Council on the Handicapped:

- serve people with all types of disabilities on the basis of functional need,
- serve people of all ages,
- provide for the optimum degree of self-direction and self-reliance as appropriate for individual consumers,
- include assistance with personal, cognitive, communicative, domestic, and other related services,
- include 24 hour, 7 day/week services, short term (respite), and emergency assistance as needed,
- not create disincentives to employment,
- be accessible to people at all income and asset levels with cost sharing as appropriate,
- be available wherever needed (e.g., home, work, school, recreation, travel),
- offer the consumer a range of employer/employee and contract agency relationships,
- provide reasonable wages and basic benefits for attendants,
- provide for training of administrators and staff of provider organizations,
- provide for recruitment and training of attendants as needed,
- provide for outreach and training of consumers as needed,
- require significant participation of consumers in program policy determination and administration.

Of these characteristics, the last two are of paramount importance. Traditionally, focus has been placed on training attendants. It is far more essential that the individual with a disability receive training to develop to

their maximum potential the skills of a teacher, psychologist, manager, evaluator, and arbitrator. As a prevention against a stagnated, paternalistic system, individuals with disabilities who understand the importance of consumer control must significantly participate in determining policy and administrative practices. Then there will be greater ensurance of the continuous development of a system which truly responds to the quality of life needs of the population it is designed to serve.

COMMENTARY

Gerben DeJong, Ph.D.
National Rehabilitation Hospital

Beyond Professional Self-Interest

Seldom have I seen a consumer perspective with respect to personal assistance so methodically and forcefully articulated. Dr. Ratzka's monograph gives consumer perspective the depth it needs to challenge professional interventions gone awry because of unexamined assumptions rooted in a professional self-interest. By using the backdrop of Sweden—where a high level of funding support would suggest more ideal conditions—Ratzka skillfully underscores how misguided assumptions and professional turf issues can compromise the aspirations of persons with disabilities.

Since I find little with which to disagree, my comments will be limited mainly to underscoring and extending some of the observations made by Ratzka. The remainder of my comments are directed to five issues: ***(1) the compartmentalization of personal assistance services, (2) the status of attendants, (3) ideological criticism, (4) proposed evaluation criteria, and (5) research issues.***

Compartmentalization of Personal Assistance Services

One of Ratzka's most important contributions is his term "compartmentalization." This term captures one of the main pitfalls of traditional in-home services, namely the degree to which various tasks in the home—from bodily care to housekeeping—are compartmentalized among various service providers. Each provider, as Ratzka notes, has its own eligibility criteria, hours of service, and service protocols. Ratzka observes that the "most far-reaching consequence—is the sense of alienation and powerlessness which the division of responsibility...breeds in consumers." The problem of compartmentalization is one of the more important reasons why consumers have turned to an all-in-one service provider such as attendants or personal assistants.

By using the term "compartmentalizaton"—rather than the overused term, "fragmentation,"—Ratzka draws attention to the turf issues inherent in professionally directed personal assistance services. However, I wish that Ratzka had gone further in tracing the roots of compartmentalization and turf consciousness. In the United States and elsewhere, one important source of compartmentalization is the commitment of allied health professionals to the medical model. More specifically, compartmentalization has its origins in the professional insecurities of home health providers whose claim to legitimacy and resources is still contingent on their allegiance to a medical hierarchy. These commitments and allegiances often result in a well-drawn line

between personal and nonpersonal care activities. Hands-on personal care is something traditionally reserved for medically supervised providers. I would like to have heard about the extent to which these conditions prevail in Sweden and how professionally erected boundaries might be used to serve the interests of persons with disabilities.

The Status of Attendants

The status of attendants or personal assistants needs clarification. Ratzka observes the ever-present tendency toward professionalism which is often legitimized by training, credentializing, and the setting of experience requirements. All these factors undermine consumer control and contribute to the compartmentalization noted above.

In the final analysis, Ratzka does not come to grips as to what the status of attendants or personal assistants might be. He rightfully notes the need for higher wages but higher wages alone will not address the need for a professional identity and professional self-esteem.

If creeping professionalism is to be avoided, it appears that attendants must, for the most part, be drawn from persons for whom the provision of personal assistance is secondary to other personal and professional goals, e.g., students, homemakers, and other persons in various stages of transition between school, home, and work life. The supply of such persons is likely to be uneven from community to community, especially in more rural areas.

Ratzka also does not come to terms with the commitment that social democracies such as Sweden and the Netherlands have toward making sure that all workers are fully protected by, and participate in, their respective social insurance programs. These programs are complex and impose burdensome paperwork requirements on employers. In the Netherlands, at least, the use of Fokus-employed attendants are designed, in part, to facilitate compliance with the country's complex labor and insurance laws. I do not intend here to erect new reasons that might be used to preclude consumer-directed personal assistance, but I do believe that these issues are not trivial especially if the egalitarian principles that drive the independent living movement are also going to be made applicable to attendants and service providers.

Ideological Criticism

Ratzka reflects on criticism made by the political left in Sweden, namely, that consumer-directed model of personal assistance is "individualistic" and "elitist." Such criticism is surprisingly more widespread in Western Europe than American readers may think. Part of the argument is that a consumer based model could only have been spawned in the United States with its commitment to individualism and capitalistic market systems. While such criticisms are not without some basis, they tend to greatly oversimplify issues and often mask professional self-interest. Some of these reactions are of the

knee-jerk variety suggesting that anything American must be individualistic. While Western European countries provide for a far more adequate standard of living for persons with disabilities, the provisions of services are often based on the assumption that consumers lack the competence with which to direct their own lives. Ratzka is correct in resisting such ideological pigeon holing but again could have gone further in uncovering the professional self-interest which sometimes motivates such ideological criticism.

Proposed Evaluation Criteria

One of the monograph's most significant contributions is its proposed consumer-oriented quality criteria to be used in evaluating different personal assistance systems. Proposed criteria include the range of tasks carried out by assistants, geographical mobility permitted, consumer control, and other criteria. I believe that these criteria, with some refinement, should be used in the United States whenever personal assistance systems are being planned, developed, or reviewed. These criteria could serve as a counterweight to the propensity of program developers to accommodate established service providers.

The development of a quality index would not be all that difficult. As Ratzka suggests, weights for each criterion would have to be developed. I would propose that a weighting system be developed in concert with a diverse but representative panel of existing and prospective personal assistance users. My guess is that the panel would exhibit a much higher degree of consensus than the panel's diversity would suggest.

Other Research Issues

Ratzka raises two other research issues which I would like to address: (1) needs assessment and (2) the effect of consumer control on independent living outcomes.

Needs Assessment. Ratzka observes that there has been great variation in estimates regarding the need for personal assistance services. The estimated need is a continuing debate in the United States as well. To resolve this debate, a two-pronged approach is needed. *First*, we need to make use of national survey research such as the Health Interview Survey conducted annually among 55,000 households by the National Center for Health Statistics. It may be necessary to append several questions to ascertain more specifically the scope of the *need* at a national level. *Second*, we need to look at the experience of states with mature attendant services programs to ascertain the probable *demand* for personal assistance.

Consumer Control and IL Outcomes. Ratzka proposes that a study be conducted to test the hypothesis that consumer-controlled personal assistance leads to greater consumer satisfaction; more productive lifestyles; and fewer medical complications resulting in unscheduled rehospitalizations.

Unlike a decade ago, such a study is now feasible given the number of attendant service users today and the varying degree of consumer control afforded by various state programs. Such a study would go a long way in solidifying the position of attendant services within the spectrum of American health and human services.

Implicit in Ratzka's proposal is a problem not adequately recognized by many. Persons with severe neurological impairments are not by definition sick but, if inactive, can compromise their thinner margin of good health leading to preventable complications and prolonged hospitalizations. Research studies have shown that the extent of unscheduled hospital re-admissions is far more serious than first thought. If the consumer-directed nature of personal assistance services can be demonstrated to foster more active lifestyles and thus prevent rehospitalizations, the consumer-directed model may have all the economic justification it may need.

In Closing

At the core of most attendant services is the provision of hands-on bodily care that has special significance for both disabled and nondisabled persons. It is in the maintenance of our own bodily care that we first learn to become independent in our childhood years. Thus, to surrender control over our own bodily care is ultimately infantalizing—a point constantly overlooked by even the best intended health and human service professionals and one of the reasons why a consumer perspective is so badly needed.

The provision of personal assistance services—especially the element of consumer control—provides remarkable insight as to how a society perceives its most disabled citizens. Nearly every aspect of how personal assistance services are rendered offers revealing insights. Ratzka's monograph outlining a consumer perspective also offers an important benchmark by which a society's attitudes and commitment to the needs of disabled persons can be evaluated.

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